

**THE ROLE OF GENDER IN PATIENT-PROVIDER TRUST FOR  
TUBERCULOSIS TREATMENT**

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This thesis is dedicated to all patients and healthcare providers in the public health system. For those who participated in the study, my sincerest wish is that I have accurately captured your experiences, desires and hopes for a health system that reflects the aspirations of the rainbow nation.

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## Abstract

**Background:** In South Africa, tuberculosis (TB) is the leading cause of death, and Cape Town is among the three cities in the country with the highest TB burden. Despite implementation of Directly Observed Treatment Short-Course (DOTS), and improvements in the organisation and delivery of TB care, poor treatment adherence challenges treatment outcomes and the health system's ability to reach international targets. TB requires long-term care, where the relationship with healthcare providers is one of the important influences on decisions to seek care and adhere to treatment. This study sought to explore and deepen insight into how trust is built and experienced between patients and healthcare providers for TB treatment in primary care settings from a gender perspective.

**Methods:** The research was located in three local government-managed clinics in the City of Cape Town's Metropole health district, similar in TB patient load and performance indicators, but differing in level of TB-HIV integrated services. A case study design employing qualitative data collection approaches (non-participant observations in clinics, focus group discussions and in-depth interviews with patients and providers) was applied.

**Findings:** Trust plays a central role for both patients and providers in treatment for TB.

On the part of patients, many expressed a deep desire and motivation to complete their treatment. However, patient vulnerability, a complex outcome of intersecting factors at all levels (personal, community and health service level), across which gender was an underlying influence, emerged as a critical influence over patient trust in providers and the health system, with consequences for a range of outcomes including treatment adherence. The ability of providers and the health system as an institution to recognise and respond to patient vulnerability and needs beyond the illness, including to access socio-economic and psycho-social support for the patient, was critical for building trust and enabling adherence.

On the part of healthcare providers, vulnerability was a consequence of a range of factors, including professional status and gender, with implications for how trust was built in patients and managers and its outcomes. Patient trustworthiness was based on judgements of competency, integrity and recognition. The ability of managers to mitigate the challenges healthcare providers faced, through providing a supportive and enabling work environment, had implications for providers' experiences and judgements of institutional trustworthiness.

**Conclusion:** Reflecting on the findings within broader national, provincial and global health policy reforms, specific strategies for building patient and provider trust in each other, and in the health system, are proposed. Recommended strategies addressing both patient and provider vulnerabilities rooted in the personal, community and health facility environment are considered. While many of the recommendations are specific to the TB and TB/HIV model of care, they have wider relevance for building mutual trust between patients and providers and enhancing the responsiveness of the health system as a whole. This is important in the context of South Africa, where the vision espoused under proposed National Health Insurance reforms towards universal coverage is transformative, even revolutionary, but its implementation and ultimate achievements are likely to be dogged by challenges of patient and provider trust in the health system, unless themselves addressed. Globally, the study's conclusions also offer important insights about patient-provider trust relevant to health system development, as well as ideas for future, related research.

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## List of Acronyms and Abbreviations

ART	Antiretroviral Therapy
CCWs	Community Care Workers
DOTS	Directly Observed Treatment Short-Course
DR-TB	Drug-resistant Tuberculosis
EN	Enrolled nurse
HCP	Health care provider
HCT	HIV Counselling and Testing
HIV	Human immunodeficiency virus
HIV/TB	HIV and TB co-infections
IPT	Isoniazid Preventive Therapy
LMICs	Low and middle-income countries
MDGs	Millennium Development Goals
MDR TB	Multidrug-resistant Tuberculosis
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NHI	National Health Insurance
NSP	National Strategic Plan
PN	Professional nurse
Sassa	South African Social Security Agency
SANAC	South African National AIDS Council
TB	Tuberculosis
UHC	Universal health coverage
W-BOTS	Ward-Based Primary Health Care Teams
XDR-TB	Extensively drug resistant tuberculosis



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*Health systems are also human systems. At their heart is a personal encounter, the interaction between the patient and the health provider - sometimes tenuous, often contested, but always with the potential for humanity and compassion (Sheikh et al., 2014, p. 1).*

## **Chapter 1: Background and Introduction**

Globally, South Africa is among six countries accounting for 60% of new tuberculosis (TB) cases (WHO, 2016a). Cape Town (Western Cape), eThekweni (KwaZulu-Natal) and Johannesburg (Gauteng) are among the three cities in South Africa with the highest TB burden (Health Systems Trust, 2016). In South Africa, TB is the leading cause of death (Statistics South Africa, 2017). The increase in TB incidence has been fuelled by the concomitant HIV epidemic, rising levels of drug-resistant TB and poor treatment adherence which together challenge the detection, management and control of the epidemic and, ultimately, the country's ability to achieve global targets for TB control (Kaplan *et al.*, 2014; South African National AIDS Council, 2017).

Treatment adherence is the outcome of a complex range of factors operating at the personal or individual level (e.g. socio-economic status, gender, motivation, mental health, availability of social support), combined with treatment regime (e.g. complexity of treatment regime, type of DOTS treatment) and health system factors (availability of services, location, availability of drugs, facility hours, relationship with healthcare providers). The relationship with healthcare providers, 'the social organization and social relationships of care' (Noyes *et al.*, 2007, p 227), is an important influence on decisions to seek care, remain in care and disclose information to providers. These actions are all the more critical in the context of TB which, given also stigma and marginalisation, requires long-term care, sustained through confidence and trust in the healthcare provider and the system.

The South African health system, and in particular the public system on which the majority of the country's population is dependent, is plagued by challenges of under-resourcing of human resource capacity and infrastructure, as well as poor stewardship, leadership and management, alongside '... rudeness, arbitrary acts of unkindness, physical assault, and neglect by nurses' (Coovadia *et al.*, 2009, p. 829). Providers working in under-resourced and unsupportive working environments are demoralised and demotivated, with implications for patient care. In the context of TB/HIV and other chronic conditions, strengthening the health system with regards to both human resources and infrastructure, as well as responsiveness, is critically important for improving patient access, health outcomes, and ultimately trust in the healthcare system.

Over the past two decades there has been a proliferation of theoretical and empirical literature exploring trust across a diverse range of disciplines including sociology, political science, governance,

organisational behaviour and public health (Lewicki and Bunker, 1996; Misztal, 1996; Hall *et al.*, 2001; Rousseau *et al.*, 2012). The burgeoning interest in investigating trust is, ironically, associated with observed decreasing levels of trust in governments across countries (Goudge and Gilson, 2005) including newly-democratising societies such as South Africa (Newton, 2001; Fjeldstad, 2004). In South Africa, although the political transformation had initially ‘... increased trust in public institutions among those who previously opposed apartheid’ (Askvik and Bak, 2005, p. 1), the slow realisation of socio-economic rights<sup>1</sup> has contributed to declining trust in government institutions over time (*ibid*), including the health system.

A key message emerging from the literature across the various disciplines is the role of trust in modern society as an enabler of economic and social wellbeing, by facilitating voluntary cooperation between individuals and systems (Askvik and Bak, 2005). With respect to health care, there is a large body of evidence pointing to the centrality of trust: ‘trust is important to health systems because it underpins the co-operation throughout the system that is required for health production’ (Gilson, 2003, p. 1461)(Gilson, 2003) . At patient level, for example, trust in providers is essential for the effectiveness of therapeutic encounters, since it encourages patients to seek care (Russell, 2005), reveal sensitive information, and submit and adhere to treatment (Hall *et al.*, 2001). Conversely, lack of trust is associated with failure to comply with the recommended treatment (Robb and Greenhalgh, 2006), failure to attend follow-up appointments, inconsistent care plans (Russell, 2005), failure to maintain long-term relationships with medical providers (Hall *et al.*, 2001), and poor patient outcomes (Thom and Campbell, 1997; Hall *et al.*, 2001; Armstrong *et al.*, 2006). Continuity of care, which allows for multiple interactions over time between patients and providers, is essential for building patient trust (Mechanic and Meyer, 2000). Equally important, although less studied, is provider trust in patients – which is important for the provision of information, and building mutual trust through enhancing patient trust in the provider, so reducing the need for monitoring (Thom *et al.*, 2011).

Trust relations in health care (Meyer *et al.*, 2008) and more generally (Giddens, 1990) are understood to operate at two levels - the interpersonal and institutional, which are interconnected and reinforce each other. Therefore, a break-down in interpersonal trust can undermine institutional trust and vice-versa. To date, there is a much larger body of literature focusing on interpersonal trust, particularly patient trust in providers, compared to institutional trust and provider trust in

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<sup>1</sup>Socio-economic rights here refer to those relating to access to basic services (e.g. housing, healthcare services, water, education, and a clean and healthy environment).

patients. While interpersonal patient-provider trust relies on face-to-face encounters, institutional trust is understood as confidence that the health system and the institutional arrangements affecting service delivery will operate in the best interests of the patient (Russell, 2005). Examples of health care organisational arrangements that influence institutional trust on the part of patients include location of facilities and institutional guarantees (e.g. scrutiny mechanisms, training, ethical commitments) (Gilson *et al.*, 2005; Gilson, 2007). The literature indicates that institutional trust is as important for providers as patients, built on aspects of the working environment, career trajectories, pay, training and supervision, and influencing their morale and motivation, with consequences for behaviours towards patients (Gilson *et al.*, 2005; George, 2007).

Patient vulnerability arising from socio-economic factors (e.g. socio-economic status, race or ethnicity, gender) as well as ill-health (Irwin *et al.*, 2006) are also identified in the literature as having a bearing on both patient trust in the provider (Doescher *et al.*, 2000; Boulware *et al.*, 2003; Riewpaiboon *et al.*, 2005) and provider trust in the patient (van Ryn and Burke, 2000; Moskowitz *et al.*, 2011). Trusting a provider can heighten existing vulnerabilities, as vulnerable patients are less likely to have the power and resources to monitor and assess providers' trustworthiness, and are therefore less likely to trust. At the same time, trusting a patient who becomes non-adherent to treatment can reflect poorly on providers and their work performance (Rogers, 2002).

Gender is an important identified source of patient vulnerability, influencing health care access (Merzel, 2000; Eastwood and Hill, 2004; Brown *et al.*, 2006; Annandale *et al.*, 2007; Kavanagh and Bentley, 2008) and patient-provider trust (Sheppard *et al.*, 2004; Riewpaiboon *et al.*, 2005; Fitzgerald *et al.*, 2010). A review of relevant literature has revealed three important gaps in relation to gender and trust. First, from the patient perspective, much of the literature has narrowly focused on women to the exclusion of men. Second, while there is an emerging body of literature examining men's health care access and trust in providers, there is a lack of gender comparative research internationally and from South Africa. Third, the influence of gender on provider trust in patients has also received limited attention.

In seeking to fill these gaps, this study sought to understand patient-provider trust relations and their implications for TB treatment adherence from a gender perspective. TB is an appropriate tracer for exploring the concepts of trust and gender for several reasons. First, trust is especially important for long term treatments for diseases such as TB. The treatment of TB entails an extensive period spanning 6-8 months, requiring multiple interactions between patients and providers, sometimes as often as daily or less frequently (weekly or monthly). Second, adherence, which has historically been used interchangeably with compliance and is understood as uninterrupted treatment, is a particular

challenge for long term treatments like TB (Sabaté, 2003), and is a major challenge in South Africa (Holtz *et al.*, 2006; Atkins *et al.*, 2010), despite adoption of the internationally accepted World Health Organization DOTS strategy (WHO, 2006a). The international evidence suggests that patient-related factors (socio-economic, ethnicity, gender), aspects of service delivery (complexity of treatment regime, staffing, drug availability etc.), and the relationship between patients and providers are explanations for poor adherence (Sabaté, 2003; Munro *et al.*, 2007). Similarly, in South Africa, poor adherence has been linked to challenges in quality of care, staff motivation and relationships between providers and patients (Dick *et al.*, 2004; Lewin *et al.*, 2005; Lutge *et al.*, 2013). Therefore, the literature, at least implicitly, suggests the importance of both interpersonal and institutional trust for patient adherence. Third, turning to providers, several South African studies point to a range of organisational challenges that TB providers face, that have implications for their institutional trust and provider behaviour towards patients (Holtz *et al.*, 2006; O'Donnell *et al.*, 2010; Wilson *et al.*, 2011). Fourth, while the literature points to the importance of mutual trust between patients and providers and its potential positive implications for adherence, there has been very little research in this area. Finally, there is strong evidence of gender differences in TB access and adherence.

This study was located in three local government-managed clinics located in the City of Cape Town's Metropole health district. This was appropriate considering that in South Africa, Cape Town is among the three cities with the highest TB burden (Health Systems Trust, 2016). A case study design employing qualitative data collection approaches (non-participant observations in clinics, focus group discussions and in-depth interviews with patients and providers) was employed. The research design and data collection approaches were appropriate for this study, as it sought to explore the 'how' and/or 'why' of complex social phenomenon and relationships (Yin, 2014, p. 4).

## **Overall research question and sub-questions**

How is trust built and experienced between patients and healthcare providers for TB treatment in primary care settings from a gender perspective?

### **Sub-question 1**

What builds trust for male and female patients in healthcare providers for TB treatment in primary care settings?

1.1 What provider-related interpersonal and institutional factors build trust in male and female patients?

1.2 How do male and female patients demonstrate trust (or mistrust) in healthcare providers?



## **Sub-question 2**

What patient-related and institutional-related factors build provider trust in patients?

- 2.1 What are the interpersonal and patient-related factors (i.e. gender, race, socio-economic status factors) which build healthcare provider trust in patients?
- 2.2 What are the institutional-related factors which influence providers' relationship with patients?
- 2.3 How do providers demonstrate trust (or mistrust) in patients and in what ways do these differ between male and female patients?

## **Sub-question 3**

Do the flows of trust between patients and providers influence treatment adherence and how?

## **Sub-question 4**

What are the implications of the study findings for management and organizational reforms and practices, and how might these reforms strengthen gender aspects of patient-provider trust relationships for TB treatment?

## **Overview and structure of thesis**

The thesis is presented in eight subsequent chapters.

In Chapter 2, I provide a review of the literature relating to trust, gender and TB, drawing on both conceptual and empirical literature. This also provides the motivation for the conceptual framework described in Chapter 3, and the justification for the methodological approach in this study described in Chapter 4.

Chapter 3 presents the conceptual framework of the study.

Chapter 4 describes case study design as the methodological approach, its application within the study and the research setting.

Chapter 5 provides a comprehensive description of the context in terms of the burden of disease of TB in South Africa, the policy approach for tackling the TB epidemic at a global, national and provincial level, and a detailed description of the case-study facilities and the communities in which they were located.

Chapters 6 and 7 present the findings. Chapter 6 presents the findings with respect to patient trust in providers and Chapter 7 with respect to provider trust in patients.

Chapter 8 discusses the findings and, reflecting also on the broader literature, draws out the study's contributions in addressing sub-questions 1-3. In addition, the initial conceptual framework of trust (outlined in Chapter 3) is developed and extended to include a more prominent role of gender, vulnerability and trustworthiness in the public health system.

Chapter 9 concludes, firstly reflecting on the implications of the study's finding for sub-question 4 (i.e. management and organizational reforms and practices, and how these might strengthen gender aspects of patient-provider trust relationships for TB treatment) and secondly on the research learnings of this study. The final conclusion argues that for informed policy and programme decisions in South Africa and other contexts, where health systems are increasingly challenged by a lack of trust, there is a need for applying and testing the revised conceptual framework (described in Chapter 8) in other settings.

*Few things help an individual more than to place responsibility upon him, and to let him know that you trust him. (Washington)*

## **Chapter 2: Literature Review**

This chapter provides an overview of current and relevant theoretical and empirical literature relating to the key areas of this study, i.e. trust, gender and TB adherence. The review is divided into the following seven sections:

1. Overview of the literature search and strategies
2. Summary of the critical theoretical literature on trust
3. Review of the theoretical and empirical literature on trust in healthcare systems
4. Key discussions and current thinking (theoretical and empirical) on gender, health and healthcare in relation to patients and providers
5. Review of the empirical evidence exploring understandings of the intersections between treatment adherence, trust and gender in the context of TB
6. Summary of the theoretical and empirical gaps and the relevance of this study.

### **Literature review search and strategy**

This literature review was conducted in two major rounds. The initial searches were carried out in 2011 (round 1) for informing the research proposal, and repeated for new references in 2017 (round 2) in order to draw and reflect on the wider literature with respect to the research findings in the final stage of writing the dissertation.

In round 1, for informing the research questions and developing the research proposal, both theoretical and empirical trust literature were gathered from the PhD supervisor and academics familiar with trust, gender and TB research. From these sources, relevant references cited in these papers were followed up. Key words used in publications were noted and became the key words used for a more systematic search of peer-reviewed editorials, journal articles, and reviews. A search for empirical peer-reviewed literature for years ranging from 2000 to 2011 was conducted on the databases CINAHL, ISI Web of Knowledge, PubMed, EBSCOHost and Google Scholar. The databases were chosen based on the content of journals housed by each database and university access. Keywords included: tuberculosis, TB, HIV, HIV/AIDS, TB/HIV integration, integration of health services, trust, reflex\*, modern\*, interpersonal trust, institutional trust, patient-provider relationships, health services accessibility, vulnerable populations, vulnerability, patient-centred communication, gender, gender-concordance, healthcare system, health system, trustworth\*. The

keywords were used for all fields (including title, abstract, keywords and full text). Articles were selected based on relevance of content and not quality (i.e. methodology, conceptual framework). The articles identified through the literature search were then used as a source for identifying additional references. This was done by looking through their reference lists which was helpful for locating more recent studies.

In the intervening period between round 1 (2011) and round 2 (2017), in order to keep up with the with newly published papers, repeated searches on the databases were conducted, search alerts (i.e. citation and keyword) were created on relevant databases (e.g. CINAHL and Google Scholar) and journals (e.g. Health Policy and Planning, Social Science & Medicine), and key researchers in the areas of trust, gender and TB were followed for publications. As relevant literature was found in the searches, additional key words were identified. This was an iterative process that continued from the initial stages of the research (2011) until the final stage of preparing the dissertation (2017).

In round 2, a final and more focused search of the literature in light of the expanded list of key words was conducted. This was complemented by a review of relevant policy documents, in order to situate the findings within the policy and programme context of the broader health system. The selection of relevant policy documents was guided by the PhD supervisor. The final collection of literature consisted of peer-reviewed journal articles, reviews, editorials and policy documents. For archiving and organising the literature, Mendeley, a reference manager was used to electronically manage the library and for later supporting in-text citations and compilation of the reference list.

## **Theoretical underpinnings of trust**

In this section, a brief over-view of the relevance of trust as a phenomenon of scholarly interest across different disciplines will be briefly described, highlighting the contributions of Luhmann and Giddens, as the key contributors to the theoretical foundations for understanding trust. This will be followed by a more detailed review of the literature regarding the various approaches for defining trust, its dimensions, bases and levels.

### ***Trust: a multidisciplinary interest***

In recent years, trust has become an area of growing interest across several disciplines including sociology (Luhmann, 1988; Giddens, 1991; Mollering, 2001; Bjornskov, 2008), psychology (Eiser *et al.*, 2002; White and Eiser, 2006), political science (Askvik and Bak, 2005; Nannestad, 2008), management (Dietz and Den Hartog, 2006; Mach *et al.*, 2010) and public health (Birungi, 1998; Hall *et al.*, 2001; Goudge and Gilson, 2005; Gilson, 2006; Ward and Coates, 2006; Thom *et al.*, 2011; Topp and Chipukuma, 2016). A key message emerging from this body of research is the importance of trust ‘... as a facilitator of democracy, social welfare, personal wellbeing, and economic prosperity’

and for enabling '... people to enter relationships of dependency and cooperation ... [and] ... avoid costly sanctioning mechanisms to defend their interests' (Askvik and Bak, 2005, p. 2). Further, trust facilitates voluntary cooperation that has wider societal benefits (Askvik and Bak, 2005).

The burgeoning interest in investigating trust is argued as not incidental, but associated with observed decreasing levels of trust in governments across countries (Goudge and Gilson, 2005), including newly-democratising societies such as South Africa (Newton, 2001; Fjeldstad, 2004). In a country like South Africa where the political transformation had initially '... increased trust in public institutions among those who previously opposed apartheid' (Askvik and Bak, 2005, p.1), the slow realisation of socio-economic rights has contributed to declining trust in government. This has been confounded by the historical race and income inequalities and low levels of trust in state institutions, contributing to South Africa being regarded as a 'low trust society'. This clearly has implications for trust in state institutions including the health system.

Giddens (1991) argues that lack of trust in public institutions is a feature of modernity, which as Beck (1992) describes is characterised by challenges about the authenticity of knowledge, consumerism, technological advances, decreasing role of the state, globalisation and a transformation to a risk society. It is not surprising then that trust is built through an iterative process (Mechanic and Meyer, 2000; Hardin, 2002), built over time (Thom and Campbell, 1997; Hupcey *et al.*, 2001) and which cannot be taken for granted but has to be won (Giddens, 1991; Meyer *et al.*, 2008). At the same time, trust is a necessity since people are reliant on expert systems (e.g. health care) to reduce the complexity of social interactions and give them more control over their lives (Luhmann, 1988).

The notions of increased citizen agency and autonomy is built on what Giddens (1991) refers to as 'reflexive actors', or the 'reflexive nature of modernity', where citizens increasingly challenge the dominant expert authority. Similarly, Birungi (1998, p. 1457) notes, that 'social practices are constantly examined and reformed in the light of knowledge obtained from the media and other sources'. However, Elliot (2002) questions whether all people are able to benefit equally and argues that the 'reflexive nature of modernity' fails to take into account the 'information poor' who do not necessarily have access to the information necessary for being reflexive, and may in fact be disempowered and disadvantaged in the era of reflexive modernisation. Therefore, while the 'information rich' might be able to seek alternate options when they lack trust in the trustee, this option might not be possible for the 'information poor', leading to '... more dependency and less reflexivity or self-sufficiency' (Meyer *et al.*, 2008, p. 183).

Considering that trust is complex, and is considered fundamental in modern society, a more detailed understanding of how it is defined and of its core dimensions is required in order to be able to operationalise it.

### ***Definitions and dimensions of trust***

It is important to note that much of the literature on trust points to the conceptual contributions of two sociologists, namely Niklas Luhmann (1988) and Anthony Giddens (1990), whose work has informed the understandings of trust across disciplines (Hardin, 1999; Mechanic and Meyer, 2000; Mollering, 2001; Gilson, 2003; Rowe and Calnan, 2006; Pearson *et al.*, 2011). While Giddens and Luhmann differ regarding the operationalisation of trust, common to both their definitions is the emphasis on the quality of social relationships and the inherent obligations (Misztal, 1996). Given the range of disciplinary perspectives around trust, a summary of some of the key definitions is presented in Table 2.1.

**Table 2.1: Defining trust**

Definition	Discipline	Source
A psychological state comprising the intention to accept vulnerability [to another] based upon positive expectations of the intentions or behaviour of another	Philosophy	Rousseau, Sitkin et al.(1998: 395)
Confident positive expectations regarding another's conduct in a context of risk	Organisational management	Lewicki, McAllister et al. (1998: 439)
The optimistic acceptance of a <i>vulnerable</i> situation in which the trustor believes the trustee will <i>care</i> for the trustor's interests (italics in original)	Public health	Hall, Dugan et al. (2001: 615)
Trust is the reliance on one person, group or firm upon a voluntarily accepted duty on the part of another person, group or firm to recognize and protect the rights and interests of all others engaged in a joint endeavour or economic exchange	Organisational management	Hosmer (1995: 393)
To trust is to believe despite uncertainty	Sociology	Misztal (1996: 18)
Trust in another person is understood as "an expectation that the other person will behave in a way that is beneficial, or at least not harmful, and allows for risks to be taken based on this expectation"	Nursing	Thom, Wong et al. (2011: 148)

While the definitions listed in Table 2.1 differ in focus, they share several important elements. Common to all is that trust is relational. Asymmetry in knowledge and expertise between the trustor (i.e. non-expert) and trustee (expert), makes the trustor vulnerable in relation to actions of the trustee. Also, implied in the definitions is that trust is a voluntary action. Another helpful way of conceptualising trust is in relation to its preconditions (Hupcey, Penrod et al., 2001: 286); 1) 'a need that cannot be met without the help of another; 2) prior knowledge and/or experience with the other; and 3) some assessment of risk or what is at stake'. The definitions listed in Table 2.1 also allude to the dimensions of trust. These dimensions include *risk, positive expectations, reliance, suspension of watchfulness and granting of discretionary powers*. Each of these elements will be considered in more detail.

*Risk* is considered integral to trust, where trust can only arise in contexts of risk (Luhmann, 1988; Giddens, 1990; Seligman, 1997; Askvik and Bak, 2005). Risk itself is derived '... from an individual's uncertainty regarding the motives, intentions and future actions of another on whom the individual is reliant' (Calnan and Rowe, 2006, p.349). This contributes to the trustor's vulnerability, where trust and vulnerability are inseparable and that trust comprising a subjective component that requires an optimistic acceptance of vulnerability (Hall et al., 2001). Offe (1999, p. 55) argues that:

*'those lacking resources (power, wealth, information) cannot afford to trust, as misplaced trust is feared to have disastrous consequences from which actors are incapable of protecting themselves through other means ...The apparent paradox is that those who are most in need of trust-based relations, cannot afford the risk involved ...'*

This suggests that 'individuals with low incomes, little education, unemployment, minorities, young people, or single parents [and greater vulnerability] may be less trusting than those with more resources' (Ross, 2011, p. 290). Similarly, in countries such as South Africa, described as a low trust society (Steenkamp, 2009), research points to persistent social inequalities and vulnerabilities in socio-economic status, educational attainment, housing and place of residence as being significantly associated with low levels of trust in government (Mmotlane et al., 2010). Gender has also been found to have a bearing on trust, and in some societies women have lower levels of social trust than men, and this has been attributed to a higher degree of risk aversion (Chaudhuri and Gangadharan, 2003).

Related to and arising from the trustor's risk and vulnerability is the notion of *expectations*. As Gilson (2003, p.1454) suggests, 'to trust someone else is a voluntary action based on expectations of how others will behave in relation to yourself in the future'. Clearly, the emphasis is on 'positive

expectations' (Barber, 1983) of the trustee 'doing the right thing' (Askvik and Bak, 2005, p. 7).

Barber (1983) elaborates that trust involves expectations that:

- The rules of order will remain constant and the basis of trust will not be affected
- Trustees will be technically competent in the roles assigned to them, with implications for the health care system and more specifically patient trust in providers
- Trustees will place the interests of the trustors above their own.

Since trust is forward looking, risk and vulnerability flow from expectations not being met in a context of uncertainty (Barber, 1983; Luhmann, 1988; Giddens, 1991; Meyer *et al.*, 2008). More specifically, the uncertainty emanates from not being able to predict nor control the behaviour of the trustee and 'expos[ing][one]self to the possibility that the other may act in a way that has harmful consequences' (Askvik and Bak, 2005, p. 6). Gambetta (2008, p.218-219) identifies possibilities of 'exit, betrayal, defection' on the part of the trustee which originate from the trustee's freedom (Seligman, 1997), over which the trustor has little control or power. This suggests and further confirms that 'trust is inherently risky' (Askvik and Bak, 2005, p. 6).

*Reliance* is linked to notions of the differences in power between the trustor and trustee and positive expectations of the trustee. Reliance is described by Hupcey *et al.* (2001, p.290) as '...emerg[ing] from the identification of a need that cannot be met without the assistance of another and some assessment of the risk involved in relying on the other to meet this need'. While Bak and Askvik (2005) suggest that trust implies dependency, others such as Meyer and Ward (2009) argue that they are distinct concepts. The distinction lies in choice (i.e. agency). A trustor chooses to trust (Luhmann, 1988; Mechanic, 1996) based on a combination of past experience (Meyer and Ward, 2009) and affective and cognitive processes (McAllister, 1995; Jones, 1996; Gilson, 2003).

The decision to suspend 'suspicious watchfulness' (Askvik and Bak, 2005, p. 8) is also derived from cues of trustworthiness of the trustee. Trustworthiness can be understood as an 'overall disposition' (Blois, 1999, p.202) or as Bak and Askvik (2005, p. 8) argue, is a 'judgement about the level of risk involved in placing trust in specific individual or institution, and is rooted in demonstrated behaviour, reputation and appearance'.

Arising from an assessment of the risk based on a combination of affect- and cognitive-based processes and the belief that the trustee will act in the best interests of the trustor, the latter grants discretionary powers to the former (Askvik and Bak, 2005). It is argued that this act increases the vulnerability of the trustor to potential exploitation by the trustee (Gilson, 2003; Rogers and



Ballantyne, 2008). Clearly, trust is likely to have different sources or bases, and a brief account is provided in the following section.

### ***Bases of trust***

The bases of trust can be broadly understood to operate at two levels; affective and cognitive. For some theoreticians such as Simmel, the emphasis is on the affective level; where trust is understood as the 'affective, even mystical, faith of man in man' and often entails a 'leap of faith' (Simmel, 1950, p. 318). For others like Misztal (1996, p. 21), trust is based on a mixture of strong personal bonds, 'good, rational reasons' and a belief that trust fosters self-interest. Similarly, Lewis and Weigert (1985) identify three bases of trust (cognitive, emotional and behavioural). Maguire *et al.* (2001) building on earlier work of Shapiro *et al.* (1992) and Lewicki and Bunker (1996) which identified three levels (calculus-, knowledge- and identification-based), suggests a more central role for control:

- *Calculus-based trust* arises from an ongoing calculation of the predictability of others' behaviour (i.e. a typical rational choice situation). When trust is abused, a penalty will be given, whereas trustworthy behaviour will be rewarded. The behaviour remains predictable as long as the partners consider the cost of other behaviour to be higher than the benefits of it. Here, trust is based on benign self-interest.
- *Knowledge-based or experience-based trust* is based on past experiences of each other and cues linked to reputation, performance and appearance.
- *Identification-based trust*, similar to Seligman's trust as familiarity and affective-trust, is based on shared social bonds, values and identity. The trustor believes in the goodwill of the trustee and identification reflects a moral duty or commitment (Lewicki and Bunker, 1996).

While the discussion on the dimensions of trust has largely been approached from the perspective of trust between individuals, trust operates at different levels (i.e. persons, institutions and systems), which will be described in the following section.

### ***Levels of trust***

Giddens (1990) and Luhmann (1988) distinguish between macro and micro levels of trust. Micro levels of trust occur between individuals, and macro level occurs at the institutional and systems and is sometimes referred to as impersonal or 'faceless' trust (Giddens, 1990). Individual trust or trust in persons is constructed along knowledge of an individual's characteristics, personality roles (Askvik and Bak, 2005) (Bak and Askvik, 2005). In contrast, institutional trust or impersonal trust as it is sometimes referred to, is understood as trust in strangers, social systems or organizations. Institutional trust is inevitable in complex modern societies (Giddens, 1990) and 'increases in

complexity decrease the possibilities of familiarity on which individual trust rests' (Barbalet, 1996, p. 80). Micro and macro levels of trust are inter-connected and reinforce each other (Giddens, 1990). Individual interactions with organisation's representatives build interpersonal trust and this in turn support and sustain 'faceless' or institutional trust.

Giddens (1990, p. 83) refers to the meeting points of interpersonal and institutional trust as 'access points of abstract systems'. Here the representative of the system is viewed by trustors as being also responsible for the system, 'although everyone is aware that the real repository of trust is in the abstract system, rather than the individuals who in specific contexts "represent it' (1990, p. 83). Therefore, as Giddens argues, 'access points carry a reminder that it is flesh-and-blood people (who are potentially fallible) who are its operators' (1990, p. 85).

The discussion till now has focused on providing a theoretical overview of trust, regarding its dimensions, bases and levels. In the next section, the application of these theoretical concepts in relation to health care will be discussed in more detail, drawing from the theoretical and empirical literature where relevant.

## **Trust relations in healthcare systems**

As noted in the introduction, in recent years there has been a growing body of research, both theoretical and empirical, documenting and exploring the importance of trust in healthcare systems (Gilson *et al.*, 2005; Robb and Greenhalgh, 2006; Rowe and Calnan, 2006; Meyer *et al.*, 2008; Pilgrim *et al.*, 2010; Rowe and Kellam, 2010; Okello and Gilson, 2015). In high-income countries, this interest has been partly driven by decreasing levels of trust in both the healthcare system and its most visible representatives, namely healthcare providers (Mechanic, 1996; Calnan and Rowe, 2008; Pilgrim *et al.*, 2010). In the United States for instance, Mechanic (1996) argues that landmark changes in the organisation and delivery of health care including managed care has eroded trust. In the United Kingdom, research has been partly driven by concerns over decreasing levels of public trust in institutions (Pilgrim *et al.*, 2010) and more specifically 'Institutional trust has also been affected by negative media coverage of scandals over medical competence in the 1990s' (Rowe and Calnan, 2006, p. 378). In low and middle-income countries, like South Africa, the interest has arisen due to discussion and debate on social capital and the broader role of healthcare as a social institution (Goudge and Gilson, 2005).

In this section, the empirical literature will be examined with respect to the role of trust in healthcare, focusing on relationships of trust between patients and providers, from each of their perspectives.

### ***Role of trust in healthcare***

As noted previously, trust can be understood to operate at the micro (or interpersonal) and macro (or institutional, systems) levels.

At the micro level, Gilson (2003, p. 1461) notes, 'trust is important to health systems because it underpins the co-operation throughout the system that is required for health production'. The balance of power between a patient and healthcare provider is unequal, arguably in favour of the healthcare provider who has the professional medical/clinical knowledge and expertise. In contrast, the patient holds relatively less power, given their health need and lack of expert knowledge. Under these circumstances, Østergaard (2015, p. 3) reasons that '[a] health care encounter can be a complex social situation. Here trust operates as a way of solving the problem of the power gap without eliminating it'. Continuity of care, which allows for multiple interactions over time between patients and providers is essential for building patient trust. It enhances the effectiveness of therapeutic encounters through:

- Encouraging patients to seek care (Russell, 2005)
- Revealing sensitive information (Mechanic and Meyer, 2000)
- Submitting to and adhere to treatment (Hall *et al.*, 2001).

Conversely, lack of trust is associated with:

- Failure to comply with the recommended treatment (Robb and Greenhalgh, 2006)
- Unwillingness to attend follow-up appointments (Mechanic and Meyer, 2000)
- Inconsistent care plans (Russell, 2005)
- Poor continuity in maintaining long-term relationships with medical providers (Hall *et al.*, 2001)
- Poor patient outcomes (Thom and Campbell, 1997; Hall *et al.*, 2001; Armstrong *et al.*, 2006) .

While patient trust in providers has been explored in a range of settings across different countries, provider trust in patients has received less attention. This, despite the literature acknowledging its importance (Arslanian-Engoren, 1995; Halldórsdóttir and Hamrin, 1997). Thom *et al.* (2011) conclude that provider trust in patients is important for several reasons. These include the provision of information, committing to a course of care, enhancing patient trust in the physician, and also that mutual trust improves cooperation and reduces the need for monitoring.

While the above discussion speaks to the importance of trust for enabling cooperation at the micro or interpersonal level between patients and providers, Gilson (2003, p. 1461) argues that 'health systems are part of the social fabric', and that trust in the health system can contribute to building

citizen's trust in other state institutions, with implications for transformational justice (Gilson, 2003). Østergaard (2015, p. 2) argues that the poor and vulnerable in society experience the health system as providing 'differential care' and have associated 'fewer positive expectations', as well as that '[t]he failure of the public health sector to create the conditions for trusting relationships can thus further contribute to the marginalisation in society of vulnerable population groups'.

In the following sections, trust in the other, from the perspectives of patients and healthcare providers, will be explored in more detail.

### ***Patient trust in healthcare providers***

Calnan and Rowe (2006, p. 349-350) describe the centrality of trust in patient-provider relations in the following way: 'The need for interpersonal trust relates to the vulnerability associated with being ill, the information asymmetries arising from the specialist nature of medical knowledge, and the uncertainty and element of risk regarding the competence and intentions of the practitioner on whom the patient is dependent'. It should be noted that while healthcare providers include a broad range of staff who are involved directly in patient care, including clinical (e.g. doctors, nurses, psychologists, pharmacists), non-clinical (e.g. social workers, counsellors, community-care workers) and support (e.g. health facility managers, clerks, cleaners etc.), the focus in the empirical literature has largely been on patients' trust in clinical staff and primarily regarding doctors and to some extent nurses. This is evident in the following definition of interpersonal trust in providers, which is understood as '... built, sustained or damaged through face-to-face encounters with health providers and is more likely to increase with long-term doctor-patient relationships' (Russell, 2005, p. 1397).

Both Russell's (2005) and Rowe and Calnan's (2006) definitions and statements on trust in patient-provider encounters raise several important issues. The asymmetry in knowledge and expertise between the patient (non-expert) and provider (expert) limits choice and creates a sense of dependency on the provider and vulnerability on the part of the patient. Provider's power is derived from several sources. The most obvious is providers' professional qualifications and expertise. The second relates to patient's vulnerability arising from the type and seriousness of the illness and the resulting dependency on providers to act in their best interests (Mechanic and Meyer, 2000). Lastly, differences in socio-economic status, race or ethnicity, gender, language and citizenship can contribute to a social distance (Battaglia *et al.*, 2003; Sheppard *et al.*, 2004; Myburgh *et al.*, 2005; Armstrong *et al.*, 2008).

In view of the asymmetry of power inherent in the relationship, which can amplify patient vulnerabilities and risks, as noted earlier, trust operates to mediate and facilitate the relationship without addressing the power differentials (Østergaard, 2015). A growing body of literature has

explored the antecedents of trust, and specifically interpersonal trust in the patient-provider relationship. There is a convergence in the literature that patient trust in providers is based on an assessment and experience of quality of care, technical competence and interpersonal communication (Birungi, 1998; Russell, 2005; Ward and Coates, 2006; Modiba *et al.*, 2011; Brennan *et al.*, 2013; Østergaard, 2015). Mechanic (1998) summarises these interpersonal qualities of healthcare providers to include competence, perceived kindness, provider agency, confidentiality and transparency. As Carter (2009, p. 393) argues with respect to the patient-nurse relationship, trust ‘... characterizes helping as the moral center of the nurse-patient relationship and ... patients’ expectations of help and caring create obligations of trustworthiness on the part of the nurse’. Trustworthiness is thus viewed as an antecedent of trust and speaks to a patient’s (i.e. trustor’s) judgement of the attributes of the provider (i.e. trustee) with respect to their ability, benevolence and integrity (Mayer *et al.*, 1995). In addition, while not explicit among these attributes, Østergaard (2015) observes that the provider’s one particular exercise of power, demonstrated through fair and predictable behaviour, is an important influence on trust and trustworthiness.

While assessments of providers’ (i.e. trustees’) trustworthiness rely on face-to-face encounters between patients and providers, judgements are also rooted in ‘faceless’ or institutional trust (Giddens, 1990). It is understood as confidence that the health system and the institutional arrangements affecting service delivery will operate in the best interests of the patient. Gilson (2003) explains that institutional trust is informed by patients’ and the public’s experience and perception that the organisation and system are supported by codes of ethics, practices, professional standards which provide them with the confidence that these institutions are trustworthy, and that standards are maintained and upheld (*ibid*). Accountability mechanisms such as licensing, ethical codes, quality controls, and disciplinary procedures to ensure standards are maintained (*ibid*) and hold its representatives (i.e. health care providers) accountable, ‘... underpins the performance of any health system because it allows patients to trust providers without any personal knowledge of the health workers representing the system’ (Russell, 2005, p. 1397).

As noted earlier, interpersonal and institutional levels of trust are interconnected and reinforce each other (Giddens, 1990). Therefore, a break-down in trust at the interpersonal level (e.g. rude providers) can undermine trust in the other (i.e. institutional trust) and vice-versa, where poor trust in the public health system following social and institutional changes, can erode trust in its role-bearers (i.e. providers).

Gilson (2007), drawing extensively from the empirical literature (Johansson and Winkvist, 2002; Watkins and Plant, 2004; Kefford *et al.*, 2005; Armstrong *et al.*, 2006) across a range of socio-

economic contexts, points to the interaction between patient trust and the critical elements of health service acceptability, which in turn shape health-seeking behaviour (see Table 2.2).

**Table 2.2: Influence of patient trust on health-seeking behaviour**

Elements of acceptability	Factors influencing patient trust
The fit between lay and professional health beliefs	<ul style="list-style-type: none"> <li>• lay constructions of health and healing and degree of fit with provider knowledge systems</li> <li>• perceived technical competence of providers, availability of drugs and necessary equipment</li> </ul>
Patient-provider engagement and dialogue	<ul style="list-style-type: none"> <li>• patients' own characteristics and attitudes</li> <li>• levels of provider respect &amp; compassion towards patients demonstrated in attitudes and communication practices, including maintenance of confidentiality</li> <li>• lack of bias or discriminatory attitudes towards patient groups</li> </ul>
The influence of health care organisational arrangements on patient responses to services	<ul style="list-style-type: none"> <li>• range of services provided or accessible through provider</li> <li>• concern that providers face incentives to pursue profit, not patient need</li> <li>• continuity of relationship, and time spent with provider</li> <li>• institutional guarantees e.g. scrutiny mechanisms, training, ethical commitments</li> </ul>

Source: Gilson (2007, Table 7.1, p. 127)

Table 2.2 points to a combination of interpersonal (e.g. provider respect), institutional (e.g. training, ethical commitments) and organisational factors (e.g. range of services provided) influencing patient trust in providers. Patient vulnerability arising from socio-economic factors (e.g. socio-economic status, race or ethnicity, gender) in addition to ill-health (Irwin *et al.*, 2006) interact with the different dimensions of acceptability, shaping the nature of patient trust which in turn influences health-seeking behaviour. The interaction between dimensions of vulnerability (e.g. socio-economic and gender) also has implications for the different dimensions of acceptability and trust relations. In a study of maternal care in Thailand, it was found that women had different worldviews depending on their socio-economic status, and this influenced the particular forms of trust they considered important, with consequences for their health-seeking behaviour (Riewpaiboon *et al.*, 2005). In a study of African-American women seeking prenatal care in the United States, race in addition to socio-economic status was an important determinant influencing the health seeking behaviour and trust in providers (Sheppard *et al.*, 2004). In the same study, continuity of the patient- provider

relationship, effective communication, demonstration of caring and perceived competency was important dimensions upon which trust was built.

The literature indicates that patient trust in providers is as important for men as for women. In a study exploring the way gender shaped health behaviours of HIV positive men initiating antiretroviral treatment in South Africa, patient trust in providers depended on the latter behaving professionally and maintaining confidentiality (Fitzgerald *et al.*, 2010). If men perceived a breach in trust, they would interrupt treatment.

While the studies described above largely focus on the interpersonal level of trust, there is an emerging body of literature acknowledging and exploring the role of institutional trust in influencing patient trust and behaviour in relation to providers (See Table 2.2 above). Studies which have examined the role of institutional factors in building patient trust seldom considered them alone, and more often considered them in combination with interpersonal trust (Topp and Chipukuma, 2016). This might be a reflection of the idea that interpersonal and institutional trust is interconnected and reinforce each other. In Uganda, low levels of trust in providers, arising from abusive provider behaviour and the absence of institutional accountability mechanisms enforcing ethical and professional practices, lead to a breakdown in institutional trust (Birungi, 1998). In South Africa, patient trust in providers was influenced by interpersonal communication and behaviour (e.g. respectful treatment), demonstrations of providers' technical competence, and institutions enabling fair treatment (e.g. disciplinary mechanisms, staff and drug availability, and payment mechanisms) (Gilson *et al.*, 2005). Even in contexts such as Sri Lanka where there are high levels of institutional trust, poor interpersonal relationships between patients and providers can influence patient treatment seeking behaviour (Russell, 2005).

The importance and influence of institutional factors shaping patient behaviour and trust are equally important for healthcare providers, and have implications for their professional and work experience, and consequences for their engagement and relationships with patients. This will be explored in the following section.

### ***Provider trust in patients and influences on provider behaviour***

This review has found that there is a growing but still small body of literature exploring provider trust in patients, either at the micro- or macro-level or both, particularly in low- and middle-income countries. This was confirmed in a recent systematic mapping review by Brennan *et al.* (2013, p. 686). They argue that '... there are clearly gaps between the areas that are being researched with the majority of the studies being conducted from the patient perspective and focusing on patients' trust in providers with providers' trust in patients being largely ignored'. Drawing on research from high-

income countries suggests that patient's socio-economic status, race and ethnicity do influence provider trust in patients (van Ryn and Burke, 2000; Moskowitz *et al.*, 2011). Robb and Greenhalgh (2006, p. 447) found that 'clinicians felt that trust should be an integral part of their relationship with patients, and in their narratives most appeared genuinely to seek a voluntary, mutually trusting relationship'. At the same time, clinicians 'subconsciously classified patients as either "deserving" or "undeserving" on the basis of such factors as their (assumed) legal status in the UK and the extent to which they had "costly" complex health and social needs ... [and raised concerns over] inappropriate attendance patterns'. (ibid). This supports Brennan's argument for recognising the central role of healthcare providers and their discretionary power as not only '... healers of the sick, [but also as] socially licensed adjudicators on contested or contestable claims by patients to illness, the need for treatment, time off work, disability benefits and so on'(Brennan *et al.*, 2013: 686).

While the above discussion suggests that provider trust is influenced by patient-related factors, these studies have largely focused on interpersonal trust (Robb and Greenhalgh, 2006; Moskowitz *et al.*, 2011; Thom, 2011) but neglect the institutional elements which are likely to shape provider behaviour and in turn their attitudes towards patients. Encouragingly, however there is a small but growing body of evidence particularly from LMICs that is providing evidence for the hypothesis that trusting, positive and enabling relationships between co-workers and co-workers and managers are necessary for co-operation, performance and ultimately patient care (Dynes *et al.*, 2013; Okello and Gilson, 2015; Kok *et al.*, 2016; Topp and Chipukuma, 2016). More specifically, studies which have explored organisational culture and trust and its influence on provider motivation and behaviour indicate that institutional factors are important influences on patient care (van der Walt and Swartz, 2002; Gilson *et al.*, 2004; Williams, 2005). Gilson *et al.* (2004) in a study of health worker performance in South Africa found a link between health worker motivation and attitudes towards patients. Other research, also from South Africa, confirms the role of inequalities in training opportunities, low staff morale and staff shortages as impacting on quality of care, as reflected in behaviours and attitudes towards patients (Ijumba, 2002; Lehmann and Sanders, 2004).

A recent systematic review by Okello and Gilson (2015) of studies exploring the influence of workplace trust relationships over motivation confirmed the significance of workplace relationships and trust over motivation of health workers. More specifically, 'motivational factors identified as linked to trust include respect; recognition, appreciation and rewards; supervision; teamwork; management support; autonomy; communication, feedback and openness; and staff shortages and resource inadequacy' (2015, p. 13). These conclusions were confirmed in a recent study of the role of workplace and interpersonal trust in shaping service quality and responsiveness in Zambian primary health centres (Topp and Chipukuma, 2016). The authors found that providers' experiences



of poor working conditions had implications for workplace trust and ultimately patient care. The authors argued that perceptions of low pay and experiences of inequitable or inefficient health centre management contributed to weak workplace trust, leading to resentment amongst providers, blame-shifting and one-upmanship. This in turn undermined teamwork, contributing to disrespectful treatment of patients. Also important was that patient's trust in provider was shaped by assessments of both clinical and interpersonal skills. 'Although patients expressed a high degree of trust in health workers' clinical capacity, repeated experiences of disrespectful or unresponsive care undermined patients' trust in health workers' service values and professionalism' (Topp and Chipukuma, 2016, p. 192).

### ***Key messages from review of literature on trust relations in healthcare systems***

The above discussion points to the importance of patient trust in providers and provider trust in patients, as well as the relevance of both interpersonal and institutional influences on the relationship. The review also supports the finding by Brennan *et al.* (2013) that there is a dearth of evidence on understanding the factors influencing providers' trust in patients and the consequences of this for patient care and health outcomes. The literature also points to the importance of the relevance of social dimensions (i.e. socio-economic, race, gender) as important factors which also influence the relationship between patients and providers. In the next section, the role of gender, one of these social dimensions, will be explored in more detail.

## **Gender, health and healthcare**

As suggested in the previous section, experiences of health (and ill-health) and the healthcare system are not the same for all individuals and groups. Experiences are shaped by socio-economic status, race, gender and other social stratifications which are context specific. In this section, the literature examining the influence of gender on health and healthcare will be examined. In addition, recognising that healthcare systems are institutions which shape the experiences of patients and healthcare providers, the gendered experience of healthcare providers will also be considered.

### ***Gender as a social construct***

Firstly, while several theoretical and particular feminist frameworks have been advanced for understanding and operationalising gender, a social constructionist perspective which views gender as system of social classification provides a useful approach for explaining and expanding our understanding of patient-provider trust through a gender lens. Gender is defined as '... the socially constructed roles, behaviours, activities and attributes that a given society considers appropriate for males, females and other genders—affects how people live, work and relate to each other at all levels, including in relation to the health system' (Morgan *et al.*, 2016, p. 1). Similarly, Sen *et al.*

(2002, p. 6) reason that gender 'permeates social institutions' and is an 'organising principle of social life'.

There are several features arising from the above understandings of gender that are important to explore in more detail. Firstly, gender is relational and is shaped by access to and distribution of power between men (dominant) and women (subordinate), with consequences for gender norms and roles. However, gender norms and roles are not universal and vary across time and space. Apart from being influenced by cultural norms and traditions, differences in gender power relations are likely to arise because of intersections of gender with other social constructs (i.e. race, class, ethnicity) and these '... axes of power are intertwined as processes that construct and are constructed by the other' (Iyer *et al.*, 2010, p. 70), which in turn determine social position (Larson *et al.*, 2016). In addition, gender like other social constructs is dynamic (Risberg *et al.*, 2009), and broader social and macro-economic changes challenge and often demand a negotiation of the power relations between men and women whilst also influencing the social positions they occupy. Therefore, as Morgan *et al.* (2016, p. 1) argue, in order to understand gender power relations it is necessary to examine multiple levels including '... who has what (access to resources); who does what (the division of labour and everyday practices); how values are defined (social norms) and who decides (rules and decision-making)'.

Until recently, 'gender', particularly in the context of health and health systems, has largely focused on and conflated 'gender' with 'women's health. As Allotey and Gyapong (2008, p. 831) reason, 'gender studies evolved from second-wave feminism of the mid-1960s ... [and] ... [t]he initial focus on women's health as a special interest topic in health and health care delivery developed in response to the perception of a major bias against women in biomedicine in general and health service delivery in particular'. At the same time, there is a growing body of literature focusing and trying to understand how masculinity, from a social constructionist perspective shapes the experience of men in the health system (Courtenay, 2000; Morrell, 2007; Jewkes *et al.*, 2009; Schneider *et al.*, 2012). In the following section, the literature examining the gendered experiences of men and women in the health system will be explored.

### **Gender and health**

Johnson and Repta (2012) speak of the institutionalization of gender, where the gendered allocation of values, expectations, roles and responsibilities is rooted in and is an outcome of political and social systems (households, culture, religion, education, media, workplace, and health care). In relation to health, there are two important institutions. From the patient (or user) perspective, the household is important. For both patients and providers, the health care system and more specifically facilities are the other. Both of these will be considered below.

### *Gender and the patient*

As Johnson and Repta (2012, p. 21) maintain, 'Institutionalized gender also interacts with systems related to race, class, sexual identity, and other social constructs to further organize individuals and groups into hierarchies of privilege ... structur[ing] people's lives in ways that both permit and limit health by influencing, for example, experiences within and access to health care systems, resulting in different exposure risks and care received'.

At the household level, gender influences intra-household resource allocation decisions and control over resources (Lester *et al.*, 2010), with important implications for being able to access health care. Men and women may also have different access to and control over resources. The extent to which women and men are economically active and are able to earn an income is likely to influence their ability to access care. However, the extent to which men and women are able to exercise decision-making power over their earnings is likely to be shaped by the cultural context and household structure. Men, traditionally being regarded as bread-winners or the primary income earner, may be able to exercise greater control than women over the allocation of household resources, including those spent on health services (Pokhrel and Sauerborn, 2004; Wamala *et al.*, 2009).

Gender influences health care access, where men and women perceive and report symptoms differently, display different health-seeking behaviour, and often receive differential patterns of care for similar illnesses and conditions (Merzel, 2000; Eastwood and Hill, 2004; Annandale *et al.*, 2007; Braitstein *et al.*, 2008; Kavanagh and Bentley, 2008). A study from a higher-income setting found that on average, women reported more symptoms than men even when their illness status was similar (Gijsbers van Wijk *et al.*, 1999). A review of health care access across a range of income settings found that men with tuberculosis and mental health problems have been found to seek health care at later stages and at a higher level of health care as compared to women (Govender and Penn-Kekana, 2008).

In highly patriarchal societies, the importance of gender concordance between provider and patient is important because of socio-cultural and/or religious norms and practices, which not only demarcate gender roles but also restrict social and physical contact between men and women (Nigenda *et al.*, 2003; Holroyd *et al.*, 2004; Rizk *et al.*, 2005). Gender and social class can thus both interact within the health system, and generate a situation where low income, low status women – with the greatest needs – have the least access to care, compared to other population groups (Iyer *et al.*, 2010). In many traditional societies, gender norms and power relations limit women's access to money and their mobility, contributing to delays in seeking health care (Shaikh and Hatcher, 2005; Govender and Penn-Kekana, 2008; Mashal *et al.*, 2008).

The fear of discrimination and abuse arising during consultations with health providers can be an additional deterrent to seeking care. These differences are particularly exaggerated when one considers highly-stigmatised diseases such as HIV/AIDS and TB. Women, through fear of being ostracised and even abused, might not disclose their status and seek care (Phaladze and Tlou, 2006; Strebel *et al.*, 2006). Men on the other hand might also experience difficulty in accessing HIV/AIDS services, especially when these services are integrated with antenatal and reproductive health services which typically target women (Schneider *et al.*, 2012).

Generally, men tend to make less use of the health care system than women across a number of settings (Smith *et al.*, 2006; WHO, 2007a; Schneider *et al.*, 2012). Masculinity and the avoidance of the sick-role (Courtenay, 2000), poor access (e.g. clinic hours), absence of a male provider and provider bias against male patients (Hancock, 2004; Smith *et al.*, 2006) have been identified as underlying causes for discouraging men from seeking care.

#### *Gender and the healthcare provider*

Calás and Smircich (1999) argue that gender is a power relation integral to the structure, function and practice of organisations. The health care system is one such example (George, 2007). Front-line positions (nursing, midwifery, and community health services) often associated with lower status and lower remuneration are predominantly occupied by women, while men traditionally occupy positions associated with being more highly trained (e.g. doctors and dentists) and higher status (WHO, 2009). Besides the structural location, gender also plays a powerful role in shaping the 'subjective experience of that location' (George, 2007, p. 41). George (2007, p. 5) argues further that 'The resulting gender biases influence how work is recognised, valued and supported with differential consequences at the professional level (career trajectories, pay, training and other technical resources, professional networks) and at the personal level (personal safety, stress, autonomy, self-esteem, family and other social relationships)'.

From a provider perspective, research indicates that gender biases and experiences in their personal and professional relationships are carried over into their engagement with patients (Kim and Motsei, 2002). Within the health care system, providers who experience poor interpersonal relations with co-workers and gender discrimination<sup>2</sup> (WHO, 2001a), which leave them feeling disempowered and disrespected, are likely to demonstrate similar patterns of disrespect towards their patients (Kim and Motsei, 2002; Mumtaz and Salway, 2007). Experiences of sexual harassment impacted on patient

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<sup>2</sup> WHO (WHO, 2001a)(2001b) defines gender discrimination as any distinction, exclusion or restriction made on the basis of socially constructed gender roles and norms that prevents a person from enjoying full human rights. In the work place it refers to issues of pregnancy, marital status and family responsibilities, and is manifested in occupational segregation, wage discrimination and sexual harassment.

care in Pakistan: 'When I leave home to come to the Basic Health Unit, I need to travel by local transport and there are men who offer a lift or pass comments. I feel so bad and insulted that when I reach the Basic Health Unit I misbehave with my patients' (Mumtaz *et al.*, 2003, p. 264). Moreover 'social geography', which Mumtaz *et al.* (2013) describe as the physical spaces (shaped by gender, caste and age) which were accessible for some individuals and groups (including community health workers), in turn influenced relationships between those women in need of care and health workers.

### ***Key messages from review of literature on gender, health and healthcare***

A key message from the above discussion is the central role that gender plays in shaping health care access for patients. Gender also configures the experiences of providers in the health care system, which in turn influences their relationships with patients. In the next section, the literature which explores the relationship between gender, health care access and trust in relation to tuberculosis will be explored in more detail.

### **TB adherence and influences of gender and patient-provider trust**

Tuberculosis remains a major public health problem across many low- and middle- income countries (WHO, 2015a). TB incidence based on notification data indicates higher incidence among men than women (WHO, 2015a). The disease primarily afflicts the poorest and most vulnerable in societies, and imposes a huge financial burden on the poor both in terms of care (i.e. health services and informal care givers) and loss of income (Lönnroth *et al.*, 2009). Of growing concern is the challenge of the dual epidemics of TB and HIV, with HIV-infection as a risk factor for TB (WHO, 2015a). Globally, 12% of the almost 10 million people infected with TB, were also HIV-positive (WHO, 2015a). Africa, including South Africa, accounts for more than two-thirds of these cases.

In many TB endemic countries, including South Africa, TB treatment subscribes to the internationally accepted World Health Organization (WHO) DOTS [Directly Observed Treatment, Short-course] strategy, which requires patient engagement with the health services between 6-8 months (WHO, 1995). The rise of TB-HIV co-infection and drug-resistant TB in countries such as South Africa, compelled the expansion of the WHO's Global Stop TB Strategy<sup>3</sup> (WHO, 2006b) in 2005, and more recently the WHO's End TB Strategy<sup>4</sup> (WHO, 2015b). Treatment adherence, in combination with case detection and cure rates, is critical for the success of WHO's previous Global Stop TB Strategy

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<sup>3</sup> WHO's Global Stop TB Strategy was launched in 2005 and aims to "reduce dramatically the global burden of TB by 2015 in line with the Millennium Development Goals (MDGs) and the Stop TB Partnership targets". The Partnership Targets, linked to MDG 6, Target 8 include 1) by 2005, detect at least 70% of new sputum smear positive TB cases and cure at least 85% of these cases; 2) by 2015, drastically reduce prevalence and death rates by 50% relative to 1990; and by 2050, eliminate TB as a public health problem (WHO, 2006b)(WHO, 2006a).

<sup>4</sup> WHO's End TB Strategy was launched in 2015 and the strategy aims to end the global TB epidemic, with targets to reduce TB deaths by 95% and to cut new cases by 90% between 2015 and 2035, and to ensure that no family is burdened with catastrophic expenses due to TB. It sets interim milestones for 2020, 2025, and 2030 (WHO, 2015b).

and the recently launched End TB Strategy. Poor adherence or defaulting, as it is frequently referred to, is associated with increased transmission, morbidity and mortality and drug resistance (Theron *et al.*, 2015). The Global Plan to End TB 2016-2020 has three sets of targets, which speak to coverage, early detection and treatment success. Treatment adherence, access to affordable treatment and support are central to achieving treatment success.

This section of the review will focus on the following. The first part will provide a brief reflection of the central debates in the literature on adherence, and will be followed by a review of specific factors which have been identified as important influences on TB treatment adherence across a range of settings, including South Africa. The sections thereafter will explore in more detail and identify the gaps in the empirical literature on studies which have explored the inter-relationships between gender and patient-provider trust in the context of TB.

### ***TB treatment adherence and underlying determinants***

In recent years there has been a shift towards patient ‘adherence’ as opposed to ‘compliance’ in relation to TB and other diseases and conditions which require long-term therapy. While compliance casts patients in a passive role and also tends to ‘blames the patient’, adherence is understood as the ‘extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider’ (Sabaté, 2003, p. 3). As Sabaté (2003, p. 3) further notes, ‘... the relationship between the patient and the health care provider must be a partnership that draws on the abilities of each ... Effective treatment relationships are characterized by an atmosphere in which alternative therapeutic means are explored, the regimen is negotiated, adherence is discussed, and follow-up is planned’.

This shift towards adherence has also encouraged a broader investigation of factors which impact on patient treatment seeking and adherence behaviour, including socio-economic, health care and care/health system related, condition-related, therapy-related and patient related factors. (Sabaté, 2003; Munro *et al.*, 2007; Noyes *et al.*, 2007; Tupasi *et al.*, 2016) (See Table 2.3 for a typology of factor influencing TB adherence).

Recent systematic reviews of both qualitative and quantitative studies suggest that, despite the DOTS strategy and other improvements in the organisation and delivery of TB care (e.g. improved drug availability, patient-centred care), patient adherence remains a challenge across a range of settings (Volmink and Garner, 2006; Noyes *et al.*, 2007; Tola *et al.*, 2015). A recent systematic review by Tola *et al.* (2015) is consistent with that of Sabaté (2003) and Volmink and Garner (2006) with respect to the range of factors (i.e. patient, therapy, health system etc.) that challenge treatment adherence. In addition, in the context of TB/HIV co-infection in countries including South Africa, dual

infection and the increased pill-burden are also identified as additional challenges for TB treatment adherence (Naidoo *et al.*, 2013; Tola *et al.*, 2015).

**Table 2.3: Factors influencing adherence to treatment for TB**

Factors	Examples
Socio-economic related	Lack of effective social support networks and unstable living circumstances; cultural and lay beliefs about illness and treatment, ethnicity, gender and age; high cost of medication; high cost of transport; criminal justice involvement; involvement in drug dealing
Health care team/health system-related	Poorly developed health services; inadequate relationship between healthcare provider and patient; health care providers who are untrained, overworked, inadequately supervised or unsupported in their tasks, inability to predict potentially non-adherent patients, Good relationship between patient and physician, availability of expertise; links with patient support systems; flexibility in the hours of operation of treatment centres
Condition-related	Asymptomatic patients; drug use; altered mental states caused by substance abuse; depression and psychological stress and knowledge about TB
Therapy-related	Complex treatment regimen; adverse effects of treatment; toxicity
Patient-related	Forgetfulness; drug abuse, depression; psychological stress; belief in the efficacy of treatment; motivation

Source: Sabaté (2003: 127)

There have been several studies in South Africa investigating TB adherence and, as noted above, taking account of the context of HIV/AIDS and drug-resistant TB (Dick, 1999; Atkins *et al.*, 2010; Cramm *et al.*, 2010; Naidoo *et al.*, 2013; Churchyard *et al.*, 2014; Birch *et al.*, 2016) . Similar to studies in other settings, a multiple range of determinants including socio-economic (poverty, unemployment, poor housing, availability of food), patient (gender, motivation, mental health, social support, substance abuser), therapy (complexity of treatment regime, co-infection and pill burden, duration of treatment, type of DOTS treatment) and health system (availability of services, location, availability of drugs, facility hours, relationship with healthcare providers) remain important predictors for treatment adherence.

Consistent across the range of studies in both South Africa and other settings, is the critical influence on treatment adherence of gender and what Noyes and Popay (2007, p. 227) describe as ‘the social organization and social relationships of care’. The influence of gender and the relationships

between patients and healthcare providers and the social support and community networks of care which support and enable adherence, will be explored in more detail in the following sections.

### ***TB adherence and gender***

TB exhibits gender disparities with respect to 'detection and notification, progression to disease after infection and disease outcome, as well as the social consequences of the disease.' (Thorson, 2014, p. 65). Across a range of low-and middle-income settings including South Africa, surveys of TB prevalence found that TB prevalence among men was more than twice as high as among women and in settings with high HIV prevalence, was even higher (Horton *et al.*, 2016). As Thorson (2014, p. 65) proposes, "Both biological sex and socially constructed gender differences are important determinants of tuberculosis and they interact to produce differences in risks and vulnerability. Furthermore, these factors interact with other social determinants to effect health outcomes."

Annually, although more men are diagnosed and die from TB (Murray *et al.*, 2014; WHO, 2015a), TB adherence remains a challenge for both men and women. Previously, these differences, particularly those relating to sex-differences in diagnosis were ascribed to sex-based immunological differences and to men having more social contacts and so increasing their risk of exposure to contagious diseases. In recent years the wisdom of this has been questioned (Weiss *et al.*, 2006). Data from a range of countries including South Africa suggest that gender-related differences in access to TB services and gender biases on the part of healthcare providers might in fact be important and additional explanations for under-diagnosis and under-notification of female TB cases (Begum *et al.*, 2001; Uplekar *et al.*, 2001; Thorson and Johansson, 2004; Cheng *et al.*, 2005; Miller *et al.*, 2013; Smith *et al.*, 2016).

Interestingly, while the evidence suggests that women have relatively poorer access to healthcare, they fare comparatively better with respect to adherence than men. Being male was associated with a higher risk of missing a scheduled appointment (Ade *et al.*, 2016) and poorer adherence across a number of African setting (WHO, 2007b; Mkopi *et al.*, 2012; Adane *et al.*, 2013; Ukwaja *et al.*, 2013; Chida *et al.*, 2015). In other settings, despite facing greater stigma and inconvenience, women were more likely than men to access health services, be notified under DOTS and adhere to treatment (Balasubramanian *et al.*, 2004). A four country study (Bangladesh, India, Malawi and Columbia) suggests that cultural and health service-related barriers hinder timely diagnosis in women rather than reflecting disease occurrence (Weiss *et al.*, 2006).

Gendered institutional norms and processes may also influence how women and men are treated by the health care system and, therefore, their vulnerability to severe disease. In India, health-care providers may deny proper treatment to certain patients (Singh *et al.*, 2002). Similarly, in Vietnam,



among the primary reasons for poor adherence amongst women were gender stereotyping on the part of doctors (Johansson *et al.*, 1999). In relation to delays in seeking care, women were described as 'shy', 'hesitant' with 'limited knowledge in health care seeking matters' and often 'not following their doctor's prescription mainly because of a need to double-check these with their husband, family and neighbours', and men in comparison were described as 'daring and open', 'willing to follow directions and prescriptions and, being the primary breadwinners, also to have more access to money and to have a decision-making power of their own, independent of the rest of the family'.

### ***TB adherence and the influence of patient-provider relationships and patient trust in providers***

Empirical studies suggest that social relationships of care between TB patients and healthcare providers are significant and important for improving patient access and treat adherence.

Observational studies have indicated that the authoritarian culture associated with TB healthcare services, combined with poor and negative providers attitudes, impacts adversely on the treatment relationship between patients and providers (Johansson and Winkvist, 2002; Holtz *et al.*, 2006). The outcome of this for patients is an experience of a lack of respect and empathy. Globally, regrettably, poor experiences of patients in the context of TB appears to be wide-spread, as observed by Noyes and Popay: 'More generally, misunderstanding and miscommunication between health-care professionals and services users appear to be common- place' (2007, p. 238). Similar experiences have been reported in South Africa, where a large national survey investigating the risk factors for TB treatment defaulting found that unfavourable perceptions of health-care workers' attitudes, and specifically relating to lack of respect, carried a 12-fold higher risk of default (Holtz *et al.*, 2006).

While the review has identified a growing body of literature investigating patient trust in providers across a number of clinical settings, there is limited evidence focusing on TB. A recent study in the Philippines of factors associated with loss to follow-up during treatment for multidrug-resistant (MDR) TB found that, in addition to the expected socio-economic, patient and therapy-related factors which challenge adherence, 'higher levels of trust in and support from physicians and nurses' were also identified as important (Tupasi *et al.*, 2016, p. 491).

In relation to TB, few studies explicitly focused on trust, from either a patient or provider perspective, although the importance of both interpersonal and institutional trust was implied in several of the studies. A study in Vietnam explored understandings and mechanisms of trust amongst male and female TB patients (Johansson and Winkvist, 2002). A key finding was that different sources of trust (i.e. staff trusting patient, patient trusting family and society, family trusting doctor and health system, and patient trusting doctor and health system) appeared to

influence the whole treatment process. Low levels of trust on the part of patients contributed to limited patient adherence with advice or treatment, and failure to follow-up.

Given the pivotal role that healthcare providers play in the treatment process and the evidence suggesting their centrality for in treatment adherence, the following section examines the studies which have explored understandings of providers' experiences in TB treatment programmes and potential pathways of influence on relationships with patients.

### ***Organisational influences on healthcare providers' experiences in TB settings and implications for trust***

There are a number of factors which shape the experiences of healthcare providers in healthcare and in TB programme settings in particular. Working in TB facilities is an occupational risk and a growing body of studies have documented the alarming incidence of TB among healthcare workers particularly in South Africa (Jarand *et al.*, 2010; Tudor *et al.*, 2014). A recent study found that healthcare workers were substantially more likely to be hospitalized with either MDR-TB or XDR-TB than were non-health care workers (Jarand *et al.*, 2010).

In addition, studies focusing on organisational arrangements (e.g. staff shortages, patient overload, drug shortages) and more general human resource challenges, particularly in resource-constrained settings such as South Africa, conclude that these factors impact on provider motivation and patient care for TB (Holtz *et al.*, 2006; O'Donnell *et al.*, 2010; Wilson *et al.*, 2011). As Wilson *et al.* (2011, p. S1104) observe, 'Excessive workload fragments health-care teams into antagonistic groups that disrupt systems. Morale needs to be maintained in the face of high volume and repetitive tasks'. In a study exploring provider experiences and perceptions of a new TB empowerment treatment programme modelled on the ART treatment programme, trust in healthcare providers emerged as an important consideration for adherence, although it was not explicitly or *a priori* studied (Atkins *et al.*, 2011). Moreover, provider's perception of patients' trustworthiness in relation to treatment adherence challenged the implementation of an empowerment model. With respect to provider-provider relationships, teamwork and experiences of trust were challenged by 'status differentials and hierarchical relationships within the clinic' (Atkins *et al.*, 2011, p. 10 of 12).

One study investigated the influence of organisational arrangements and institutional factors on provider performance in TB DOTS programmes and trust in patients in South Africa (van der Walt and Swartz, 2002). The study identified the role of task-orientation, which means that healthcare is broken down into component tasks, performed by different providers. Therefore, providers are "allocated to tasks rather than to patients", which challenges patient-centred care (van der Walt and Swartz, 2002, p. 1001). In another study of the organisation of health care work, and specifically

DOTS in primary care clinics in Cape Town (South Africa), it was concluded that ‘...rituals [DOTS] act to reinforce asymmetrical relations of power between different constituencies, and to strengthen conventional modes of provider–patient interaction, through the medicalisation of the illness to create a sustainable ‘sick role’, and second, through constructing the patient as a passive, non-trustworthy recipient of care in need of monitoring and control’ (Lewin and Green, 2009, p. 1467).

Together, these studies point to the importance of organisational arrangements and institutional factors which build coherent multi-disciplinary teams, promote institutional trust on the part of providers, and in turn influence their behaviour towards patients.

### **Concluding remarks**

While there is a growing body of literature, and increasingly from LMICs, exploring trust in healthcare and systems, research attention is focussed on limited areas. These include 1) interpersonal trust in patient-provider relationships, to the neglect of the role of institutional and systems level trust; 2) the patients’ perspective, ignoring the providers’ perspective and mutual or reciprocal trust between patients and providers.

Further, while studies have started to explore how patient vulnerability is shaped by gender and other social stratifications (e.g. socio-economic status, ethnicity, sexual identity etc.), these studies have largely focused on how gender and other social stratifiers influence treatment seeking behaviour and healthcare access, and consider less their implications for trust, from either the patients’ or providers’ perspective. Moreover, from a gender perspective, this review has only been able to locate studies which have either focused on men or women alone, but not in the same study, suggesting a gap in gender comparative research. Finally, there is a research gap in the TB literature investigating the implications of mutual patient-provider trust relations for adherence, exploring both interpersonal and institutional factors through a gender lens.

## Chapter 3: Conceptual Framework

In this section, a framework for understanding and exploring the ways in which gender influences trust relations for TB care in primary care facilities will be described. This framework is based on theoretical premises and empirical findings from previous research, drawing specifically from a social constructionist understanding of gender (Courtenay, 2000; Sen *et al.*, 2002; Krieger, 2003; Annandale *et al.*, 2007) and trust relations in health care (Gilson *et al.*, 2004, 2005; Calnan and Rowe, 2006; Gilson, 2006). This framework also draws on concepts of workplace trust (Gilson *et al.*, 2005) and more specifically on organisational and institutional influences on provider behaviour. A social constructionist perspective is considered appropriate for this framework since gender and trust are both relational concepts which have to be understood in the historical, socio-political and cultural contexts in which they are embedded.

In the framework, patient-provider trust is bi-directional in that both patient trust in the provider and provider trust in the patient are important, and warrant exploration and understanding. Drawing from Russell (2005, p. 1397) patient trust in providers is understood here as 'patient confidence that the health care provider and the health system which they represent, works for the best interests of the patient and has the technical and personal competencies to do so'. This definition incorporates both competence trust and intentional trust. Competence trust is where the patient has the expectation that health care providers and the health system have the skills and abilities necessary to carry out their work actions (Mayer *et al.*, 1995; Calnan and Rowe, 2006). Intentional trust is where the patient has the (positive) expectations that health care providers and the health system works in the interests of the patient (Alaszewski, 2003; Rowe and Calnan, 2006).

Drawing from Thom *et al.* (2011, p. 149) provider trust in patients is understood as provider confidence that the patient and the health system enable the provider to offer appropriate care for the patient in a way that allows the provider to fulfil his/her professional responsibilities and is not harmful for him/her either personally and/or professionally. Common to both patient and provider trust are elements of risk, vulnerability, positive expectations, reliance and the granting of discretionary powers (Giddens, 1990; Askvik and Bak, 2005; Gilson *et al.*, 2005; Rowe and Calnan, 2006).

Behaviour and attitudes of providers and patients are both independent and dependent factors in the patient and provider trust relationship. They are independent in that they are factors which influence the nature of the trust relationship (Gilson *et al.*, 2005). At the same time, attitudes and

behaviours of providers and patients are also an *outcome* of the trust relationship (Gilson *et al.*, 2005; Russell, 2005).

Examples of behaviours on the part of a patient demonstrating a lack of trust include failure to engage with providers openly, unwillingness to fully disclose relevant information and seeking care from alternative providers (Calnan and Rowe, 2006, 2008), which in turn impacts on treatment adherence. TB adherence is a critical patient behavioural outcome and, drawing on existing definitions of adherence by Sabaté (2003), is understood as the extent to which patients follow the prescribed treatment regimen - demonstrated through taking their medication, consulting with health care providers and following any other provider treatment-related recommendations - arising from mutual agreement between themselves and the provider. Therefore, adherence is not only a consequence of patient trust in providers but is the *outcome* of mutual patient-provider trust.

Turning to providers, examples of behaviours demonstrating a lack of trust in patients might include an emphasis on observing patients taking their treatment (as opposed to self-administered), excluding patients from decision-making, and enforcing a task-orientated approach towards implementation of the treatment programme (van der Walt and Swartz, 2002; Rowe and Calnan, 2006). Van der Walt and Swartz (2002, p. 1001) describe task-orientation, and specifically as it relates to nursing, as ‘...an organisational practice which is orientated to completing discrete tasks. In practice, this means that the nursing care required by a patient is broken down into a set of tasks, and typically performed by different practitioners. Nurses are allocated to tasks rather than to patients’.

Trust is understood to operate at two levels; namely inter-personal and institutional, and the interaction between these levels influences patients’ and providers’ behaviours and attitudes towards each other (Giddens, 1990; Gilson *et al.*, 2005; Russell, 2005; Calnan and Rowe, 2006). Further, inter-personal and institutional levels of trust are interconnected and reinforce each other (Giddens, 1990), and a break-down in trust in one undermines trust in the other with consequences for overall trust.

For patients, interpersonal trust is based on judgements about a combination of cognitive- (e.g. assessment of technical competence) and affect-based (e.g. sincerity, empathy, reliability of communication) provider behaviours and attitudes (Hall *et al.*, 2001; Gilson *et al.*, 2005; Riewpaiboon *et al.*, 2005). Similarly, for providers, interpersonal trust is also likely to be influenced by a combination of cognitive- (e.g. understanding the provider’s instruction, following the treatment plan) and affect-based behaviours and attitudes (respect, honesty, reliability of

communication, etc.) on the part of patients. For both patients and providers, a poor assessment of these elements based on experience can undermine trust in the other.

In complex social systems (Luhmann, 1988; Giddens, 1990), institutional factors defined as “rules, laws, norms, customs, rather than organisations” (Ben-Ner and Putterman, 1998, p. 37) which influence provider behaviour (Goold, 2001) build institutional trust<sup>5</sup> on the part of patients (Gilson *et al.*, 2005). Broader health policy reforms and organisational initiatives to strengthen organisational accountability are important for building institutional trust. Institutional trust then enables the patient (trustor) to trust in the provider (i.e. trustee or organisation’s representative) (Luhmann, 1988). Institutional factors and organisational arrangements, including working conditions, are also important for supporting and enabling providers to fulfil their roles and responsibilities and build a trusting relationship with patients (Gilson *et al.*, 2005). Policies and codes of conduct which promote and uphold the rights of providers in relation to patients, and enforcement of practices of infection control (e.g. patients and providers wearing protective masks) have implications for provider vulnerability and institutional trust.

It is suggested here that both patients’ and providers’ behaviours and attitudes are influenced by gender in ways that then influence trust between them. Gender is understood here to comprise three dimensions (WHO, 2001a, 2007a), which influence treatment seeking behaviour and patient-provider trust:

- Roles: refers to ways in which the division of labour between men and women and ‘who does what’ in terms of household and income generating responsibilities
- Norms: refers to societal expectations of how men and women should behave, and influences social expectations of appropriate roles and behaviours for men and women
- Relations: refers to how access to and control over resources<sup>6</sup> and power as well as roles and responsibilities are distributed between men and women.

Socially constructed gender roles, norms and relations affect perceptions, experiences and ways in which men and women as healthcare users and providers define their health (with respect to users) and access to resources. For patients or users, this in turn contributes to gender-based differences in treatment seeking behaviour and their interaction with the health care system across a range of

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<sup>5</sup> Examples of health care institutions include “professional and ethical codes; training and qualification systems; the capacity of the health system to ensure that providers can perform effectively, for example by assuring adequate drug supplies; remuneration systems that shape professional practice; and procedures for ensuring health worker accountability” (Mechanic and Meyer, 2000; Straten *et al.*, 2002, cited in Gilson *et al.* (2005, p. 1419)).

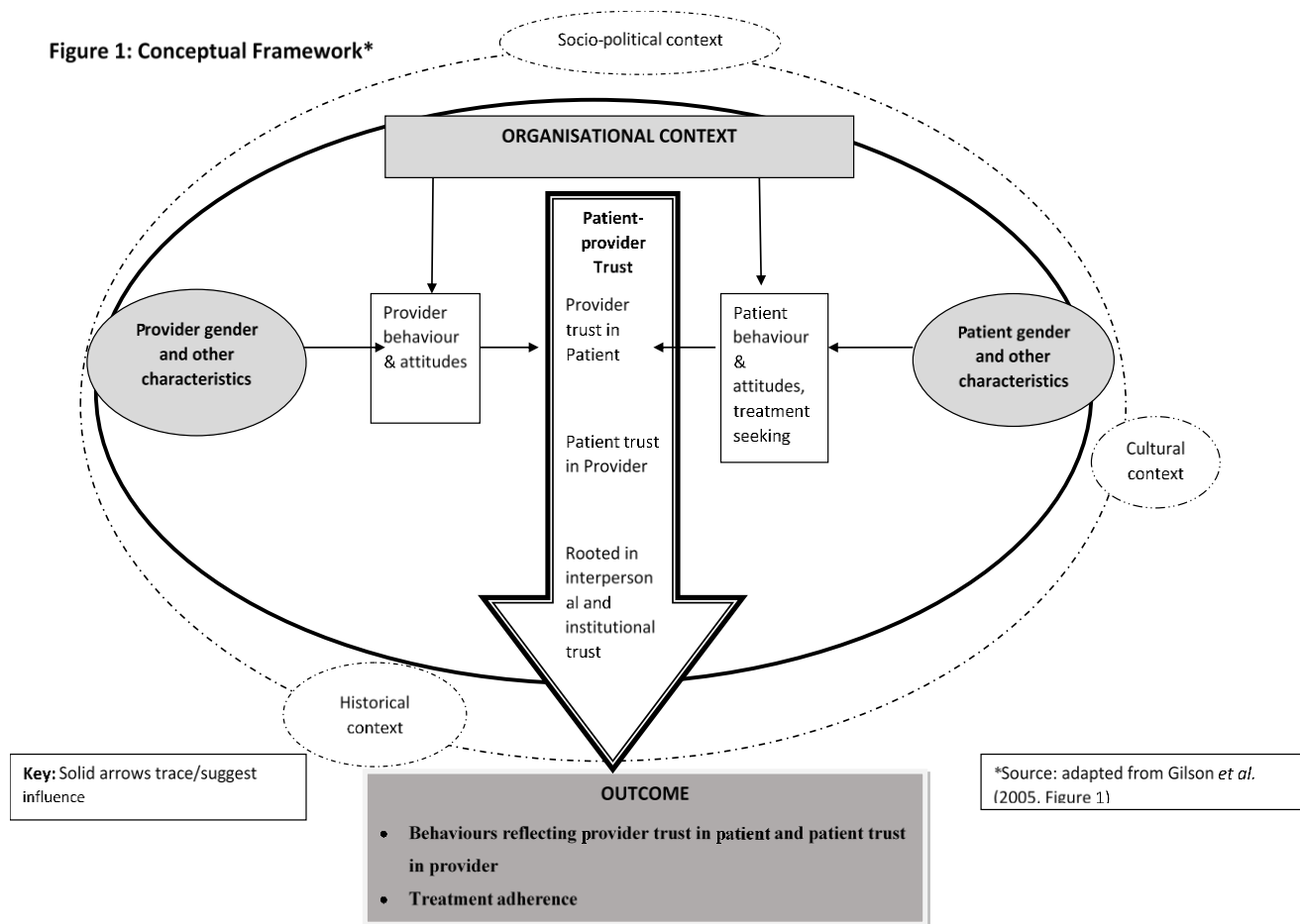
<sup>6</sup> Information, decision-making, education, time, income, economic resources, self-esteem, confidence (WHO, 2001a).

conditions and services including TB (Bertakis *et al.*, 2000; Crampin *et al.*, 2004; Braitstein *et al.*, 2008; Govender and Penn-Kekana, 2008). Gender not only influences patient treatment seeking behaviour but also influences provider perceptions and influences their interaction with patients. For providers, gender influences their own assessments of their vulnerability in relation to their personal and professional lives.

It is suggested here that for TB treatment, gender influences patient and provider behaviour and attitudes in ways that then shape the nature of trust between them, demonstrated through self-reported experiences, perceptions and expectations. More specifically, gender influences the nature of the trust relationship through its interaction with specific elements of trust including risk, vulnerability and positive expectations (Askvik and Bak, 2005). For instance, gender roles which define domestic and work responsibilities for men and men often have implications for treatment seeking. If hours of work or domestic responsibilities are not compatible with facility timings, it implies that patients will not be able to meet their facility appointments and there is a risk for treatment adherence. The examples described are not meant to be limiting or exhaustive but provide a preliminary set which can be tested and expanded. A social constructionist perspective, exploring the relationship between gender and trust, suggests that other social dimensions (i.e. race, education, socio-economic status) interact with gender to influence trust between patients and providers.

Lastly, the historical, socio-political and cultural context will also exert an influence on patient and provider trust (Luhmann, 1988; Ward and Coates, 2006) (Luhmann, 1988; Ward and Coates, 2006). This is particularly relevant in investigating trust relations in low trust societies like South Africa (Bak and Askvik, 2005), where perceptions and trust of government and its different departments might influence treatment seeking behaviour.

Figure 1: Conceptual Framework\*





## Chapter 4: Methods

This chapter describes the methodological approach of interpretative multiple case studies which was adopted for this study to explore the constructs of trust and gender in patient-provider relationships in primary care settings. The research focused on TB services (i.e. cases) in three local government managed primary care facilities located in Cape Town. Data were gathered through non-participant facility observations, interviews and focus group discussions with patients seeking TB care, and healthcare providers tasked with their provision. Table 4.1 below summarises the methodological approach, the details of which are expanded in this chapter.

This chapter comprises several sections. The initial stages of research design, study settings, sampling, case and participant selection, and choice and design of data collection tools are explained in detail. This is followed by a description of the process and experience of data collection. Next, the analytical approaches for data analysis and tactics for building methodological rigour are described. This chapter concludes with an account of reflexivity and ethical considerations.

**Table 4.1: Methodological approach**

Methodological approach	Interpretative case study
Case design	Multiple with a literal replication strategy
The cases	TB services in primary care facilities which were either partially- or fully-integrated with HIV services
Data collection tools	Non-participant facility observations, interviews and focus group discussions
Data analysis	Individual case analysis applying inductive and deductive approaches and cross-case synthesis applying comparative analysis
Research participants in each case	<ul style="list-style-type: none"><li>• Patients on TB treatment (first time and repeat cases)</li><li>• Health care providers tasked with provision of TB services (i.e. doctors, nurses, TB adherence counsellors, TB assistants, DOTS supporters, community care workers)</li><li>• Managers (i.e. healthcare facility, programme and non-governmental organisation)</li></ul>

### Study setting

The study was conducted in the period September 2012 - March 2014. It was located in two of the City of Cape Town's eight health sub-districts. This was appropriate given the TB disease burden in the City, which will be described in more detail in Chapter 5.

Within Cape Town, primary care facilities are managed both by City Health (the City of Cape Town's Health Directorate) and the MDHS (Metro District Health Services, falling under the provincial government of the Western Cape), which together were responsible the provision of health services to a population of approximately 3.8 million at the time of the study (Statistics South Africa, 2011). City Health and MDHS are also the principal authorities responsible for TB Control Programme activities in Cape Town, supported by local NGOs with respect to treatment and follow-up services in

the facility and community. While all primary care facilities (those under the authority of both City Health and MDHS) provided TB diagnostic services, TB treatment was historically provided by City Health and HIV treatment by MDHS. At the time of the study, efforts to integrate TB and HIV services at the primary care level, within a single facility were being phased in, with some facilities being more advanced and further in the process of integration.

## **Research design**

The study employed a case study approach design (Creswell, 1998) which is appropriate for studies exploring the 'how' and/or 'why' of complex social phenomena and relationships (Yin, 2014, p. 14). Yin (2014, p. 16) defines a case study as an empirical enquiry that "investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident". Case study design is rich in context and typically combines several data collection methods, distinguishing it from other research designs (Yin, 2014).

This methodological approach was appropriate for exploring and understanding the construction of trust between patients and providers, and the influence of gender on patient-provider relationships, for several reasons. Context was particularly relevant for this study exploring the influence of multiple contextual factors (e.g. gender, race, socio-political, historical) on human relationships (e.g. trust between patients and providers). Second, given the focus of the research on the study of relationships in health care settings, the emphasis was on how participants in patient-provider relationships made meaning of their experiences, allowing for description and interpretation of those experiences in settings where they occurred (Mack and Woodsing, 2005).

Case study research can be conducted from a positivist, interpretive or critical knowledge paradigm. In this study, an interpretive perspective was adopted, recognising the social construction of reality, and attempting to understand the phenomena of focus (i.e. trust, gender, treatment adherence) through the meanings that people (i.e. patients and providers) ascribed to them. Multiple case studies were used to allow for comparison across cases and/or replication of the findings as the cases were analysed.

Qualitative research methods were also relevant for this study as such approaches are '...especially effective in obtaining culturally specific information about the values, opinions, behaviours, and social contexts of particular populations' (Mack and Woodsing, 2005, p. 1). Qualitative methods allowed for the exploration of socio-cultural, historical and political factors of specific variables of interest (e.g. trust, risk, vulnerability, gender norms, stereotyping, gender relations, attitude and relationships of individuals) that were less suitable for inquiry using quantitative approaches (Mack and Woodsing, 2005).

### ***Case selection and sampling strategy***

A multi-case design with a literal replication strategy (Yin, 2014) was used, requiring the purposive selection of similar cases. The research was, therefore, located in three purposively selected case study TB services located in City Health (local government) primary care facilities.

The need to focus on a similar group of health facilities (i.e. subjects) that offer the opportunity for understanding a certain phenomenon (i.e. trust and gender) (Patton, 2002), required that the TB services located within health facilities were selected using criterion sampling - which involves selecting cases that meet pre-determined criteria and are information rich (Patton, 2002). For this study, criterion sampling was operationalised in two steps. The first step was to compile a list of all primary care facilities which provided TB services and were similar with respect to the following criteria:

- Medium-size facility with respect to TB patient load (between 200 and 500 patients on TB treatment per annum). Facilities with patient-load of less than 200 were excluded since they would pose challenges for recruitment of participants.
- Well performing TB services, judged by TB cure rates of at least 80%. Facilities with high TB cure rates were also more likely to have patients who were adherent, which was a focus of the study.
- Model of TB/HIV integration: TB clinic which offered partially-integrated services (i.e. On-site HIV testing and referral for HIV care); or TB clinic which offered one-stop service through the provision of both TB (screening, diagnosis and treatment) and HIV services (testing and treatment).

Based on step 1, a list of all facilities in the City of Cape Town's eight sub-districts was compiled. In consultation with the City Health Directorate, facilities which were existing research sites were excluded from the list, since facility managers were concerned that additional research might impact adversely on the facilities' work flow and operations. Final selection was based on considerations of approval of the facility manager, geographic accessibility and safety, since several facilities were located in high-risk communities. Variation was present in terms of location of cases (i.e. Black African or Coloured townships), patient (i.e. gender, race and socio-economic status) and healthcare provider profile (i.e. gender, race and professional background).

### ***Selection of research participants within each case***

Within each case, participants included healthcare providers and patients. The participants for this study were purposefully selected. Purposive sampling and selection aims to select participants according to pre-determined criteria relevant to the research objectives (Mack and Woodsing, 2005;

Guest *et al.*, 2006). Also, this approach to sampling is theoretical as opposed to being statistically grounded. Further, as noted by Denzin and Lincoln (1994, p. 202), in purposive sampling, ‘researchers seek out groups, settings and individuals where ... the processes being studied are most likely to occur’. With respect to this study, purposive sampling ensured that from each case a diverse range of TB providers and patients were selected and that the results emerging from the sample population produced the type of evidence necessary for exploring the research questions.

#### *Selection criteria for patients*

The inclusion criteria for recruitment of patients for focus group discussions (FGDs) and in-depth interviews were:

- Male and female patients, since the focus was on exploring the experiences of both men and women
- Patients who were on treatment for TB and TB/HIV co-infection
- Patients who were TB treatment adherent<sup>7</sup>: for the purposes of this study, adherence was understood as the extent to which patients follow the prescribed treatment regimen - demonstrated through taking their medication, consulting with health care providers and following any other provider treatment-related recommendations.
- The patient was in the continuation phase<sup>8</sup> of TB treatment and had been on treatment for at least two months. The phase of treatment and length of time in treatment was necessary in order for patients to be able meaningfully to comment on their experiences in the facilities and relationships with healthcare providers
- Patients taking their treatment either in the facility or in the community under the supervision of a TB provider (TB nurse, community DOTS supporter, CCW)
- Patients with a permanent address to aid recruitment and ensure that we were able to follow-up if necessary.

Patients with substance abuse problems, who were mentally incapacitated or with drug resistant TB were excluded from FGDs and interviews. Interactions between providers and patients with drug-resistant TB were captured during facility observations, since the focus of the observations was to

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<sup>7</sup> Poor adherence and defaulting are related but not synonymous terms. Defaulting refers to a patient who no longer seeks treatment at the facility and has disengaged from the system. Poor adherence is operationalised here to refer to someone who still collects their medication but perhaps is not rigorous about taking their treatment.

<sup>8</sup> The *intensive phase* is when four different drugs in tablet form are given for five days a week, for two to three months. The second phase is the *continuation phase*, in which two drugs are given for five days a week, for four to five months. First-time TB clients must be treated for six months, while clients who have had TB before must take TB medicine for eight months. If there are side effects from the medication, the client must return to the clinic. Sputum tests are taken again after two months on treatment to check for progress, and at five or seven months to confirm whether the client is cured.

capture the operation of TB services within the facilities in its entirety, including all patients requiring TB services (e.g. paediatric and drug resistance TB patients). Observations of other services in the facility were captured since these were expected to also influence patients' overall experiences in the facility.

#### *Selection criteria for healthcare providers*

Healthcare providers included treatment support staff (e.g. doctors, TB nurses, TB assistants, TB DOTS supporters, adherence counsellors, CCWs, social workers) and in a few instances administrative (e.g. TB clerks) staff who interacted with patients. The inclusion criteria for recruitment of providers for FGDs and in-depth interviews were:

- Clinical (nurses, doctors) and non-clinical (TB assistants, TB DOTS supporters, adherence counsellors, CCWs and social workers) healthcare providers who were responsible for one or more of the following functions: overseeing the diagnosis, treatment and psycho-social support of TB patients either at the clinic (e.g. TB nurse, doctor) or in the community (e.g. DOTS supporter, CCW)
- Minimum of six months in their current role

### **Data collection tools**

For each of the three cases, data was collected in three stages:

1. Non-participant observations (Stage 1)
2. Focus group discussions with providers and patients (Stage 2)
3. In-depth interviews with patients and providers (Stage 3)

The stages were undertaken sequentially to allow for stages 2 and 3 to build on and be informed by stage 1 regarding design and content. Also, while the three stages and the instruments (i.e. observations, FGDs and interviews) were distinct, they were inter-related and comprised three different angles for exploring the research questions. The following sections describe the data collection tools, their relevance and ways in which they were operationalised in the study.

#### ***Stage 1: Non-participant observation (NPO)***

NPO refer to the process of observing and documenting activities and events but where the researcher does not interact with the participants (Thorogood and Green, 2009). Observations are regarded as the 'gold standard' of qualitative research and have a number of advantages of relevance for this study's objectives and design (Mack and Woodsing, 2005):

- Provided the opportunity for gaining a deeper and richer understanding of the cases and the wider context

- Enabled the field team to become familiar with the life of the facility, the key actors, routine practices, daily activities, relationships among and between staff and patients, norms, behaviours and the cultural milieu
- Allowed for the field team to build relationships with key stakeholders, identify gatekeepers, and establish a presence in the facility
- Allowed for the identification of appropriate strategies for recruiting participants for the FGDs and in-depth interviews
- Provided valuable information for designing the focus group guidelines and interview guides in stages 2 and 3, respectively, through 'ensur[ing] the[ir] cultural relevance and appropriateness' (Mack and Woodsing, 2005, p. 16).

Observations were carried out over a period of 2-3 weeks in each of the facilities. While the focus was primarily on the facility, observations were also conducted of patient-provider relationships outside of the facility. Observations were carried out both in TB-specific and non-TB specific areas in the facilities. These included general and TB waiting rooms, treatment rooms where DOTS were being administered and staff rooms. Community visits accompanying DOTS supporters and CCWs were also undertaken. The focus was on the interactions between providers and patients, providers and each other and patients and each other. Attention was also paid to the gender-specific nature of interactions and whether more generally providers (patients) treat patients (providers) differently and if so, 'which' patients (providers) were these and how were they treated.

### ***Stage 2: Focus group discussions (FGDs)***

FGDs were held with patients and healthcare providers. FGDs have several strengths. FGDs are particularly useful for '[i]dentifying group norms, [e]liciting opinions about group norms and [d]iscovering variety within a population' and have several advantages over other methods in that they '[e]licits information on a range of norms and opinions in a short time [and] [g]roup dynamic stimulates conversation, reactions' (Mack and Woodsing, 2005, p. 52). Another advantage of FGDs (compared to individual interviews) is the interaction among group participants (Smithson, 2010) which provides the researcher with a chance to observe and study the process of collective sense making and to learn the language and vocabulary used by the participants (Frith, 2000). Also, with respect to this study, since the research topic was a relatively unexplored area and the phenomena of interest (i.e. trust and gender) were not easily observable, a FGD, guided by open-ended questions, was a necessary step in the development of the individual interview guides (Thorogood and Green, 2009). 'This is critical for the design of interviews that are acceptable to respondents and

capable of generating reliable and valid data across the population' (Thorogood and Green, 2009, p. 57).

Homogeneity of participants within a FGD is encouraged since it is believed that they '... are generally more comfortable and open with each other, whereas mixed sex, ethnic, or socioeconomic groups make it more difficult to achieve a high degree of group interaction' (Keown, 1983, p.66). Homogeneity can be based on socio-economic status, sex, race, ethnicity, religion, etc. In this study, with respect to patients, homogeneity was based on sex, where single-sex FGDs (i.e. a FGD with either only male or female participants) would be carried out. The rationale for single sex FGDs was considered appropriate for exploring sensitive topics such as gender, where men and women are likely to have different and sometimes opposing views and perspectives. Besides encouraging participation, single sex groups might also provide the space for participants to more freely express their opinions without fear of being reproached or being judged by members of the opposite sex. However, for practical reasons, mixed sex FGDs were actually held.

With respect to healthcare providers and homogeneity, composition of groups was based on position and role in the facility. FGDs were held with non-clinical, NGO-employed staff who were of similar rank. Supervisors, managers and nurses were excluded from these FGDs since differences in professional position might discourage participants lower in the professional hierarchy from disclosing fully and communicating candidly their experiences and opinions in the presence of those higher in the professional hierarchy.

FGDs were conducted in an open-ended, semi-structured way to encourage participants to elaborate on their answers, and this was also more likely to yield detailed accounts of participants' experiences and their meaning of these experiences. FGDs were conducted by members of the field team who matched the demographics of the participants for race and language of choice (isiXhosa, English or Afrikaans).

In the FGDs and later in the in-depth interviews with both patients and healthcare providers, trust was not explicitly or directly asked about, rather it was investigated indirectly through exploring topics that would illuminate events and experiences under which patient and provider trust was constructed (see Appendices 8-11). The purpose or hypothetical underpinnings of this thesis was not to establish whether trust existed, what patients and providers understood by trust and whether it had changed, all of which could be investigated through quantitative methods including surveys and trust scales. The purpose was to understand how trust as a multi-dimensional concept was constructed and experienced, contextualised in time and place along the dimensions of risk, vulnerability and positive expectations. These dimensions of trust were informed by the theoretical

literature as described in Chapters 2 (Literature Review) and 3 (Conceptual Framework). Asking patients (or health care providers) directly whether or not they trusted providers (patients) and the health system, may have led to formulaic responses. Investigating trust indirectly through careful probing of participants' description of their vulnerabilities, expectations, perceived risks and whether expectations were met, provided a more nuanced and context-specific description of the construction of trust.

Topics that were covered in the FGDs with patients included previous encounters with the health facility, experiences of TB services with respect to organisation and healthcare providers, relationships with TB healthcare providers, interactions with providers that stood out for them (positively or negatively), and ways in which these impacted on their treatment adherence (Appendix 8). In the FGDs with providers, topics covered included workplace challenges, motivations to work in the healthcare sector, relationships with colleagues, supervisors and management, and relationships with patients (Appendix 10).

### ***Stage 3: In-depth interviews***

In-depth interviews with both patients and healthcare providers were conducted. In-depth interviews allow for the exploration of '...individual experiences, opinions, feelings, [a]ddressing sensitive topics... [e]licits in-depth responses, with nuances and contradictions [and] [g]ets at interpretive perspective, i.e., the connections and relationships a person sees between particular events, phenomena, and beliefs' (Mack and Woodsing, 2005, p. 30).

The topics covered were guided mainly by the theoretical and empirical literature and emergent issues from the FGDs. '[S]ince providers and patient views about an encounter may not correlate hearing from both sides may yield valuable information about how to manage, sustain, and improve these complex relationships' (Ratanawongsa *et al.*, 2011, p. 40). Topics covered under the in-depth interviews with patients included their personal background, living conditions, social networks, their illness and treatment journey, adherence challenges and enablers, their relationships with and expectations of healthcare providers (Appendix 9). With respect to providers, topics included their personal background, personal motives, career trajectories, working conditions, relationships with and expectations of patients, colleagues, supervisors and managers (Appendix 11).

### **Data collection**

The data from each of the three cases was collected between October 2012 and February 2014 (see summary table below). As noted earlier, in each of the cases, data collection occurred in three stages. Prior to the commencement of fieldwork, through arrangement with the three facility managers, staff was invited to participate in a meeting with the research team. In this consultative



meeting, the purpose of the research, duration of the fieldwork, the implications of the research for the operations of the facility and expectations of providers were discussed.

Once approval has been obtained for the research, data collection commenced, which on average, on a part-time basis was 12-15 weeks per case. The field team comprised of the principal investigator and between two and three research assistants. Research assistants were postgraduate students from the disciplines of anthropology and social development with experience in qualitative research.

**Table 4.2: Summary of data collection across cases (September 2012-March 2014)**

	Case 1	Case 2	Case 3
<b>Data collection period</b>			
	September-December 2012 (4 months)	April-July 2013 (4 months)	January-March 2014 (3 months)
<b>Methods for data collection</b>			
<b>Non-participatory observations</b>	15 days per facility including 2-3 days accompanying DOTS supporters and CCWs on visits to patients in the community		
<b>Focus group discussions</b>			
<b>Patients</b>	<ul style="list-style-type: none"> <li>Community DOTS (1 male, 4 females)</li> <li>Facility DOTS (3 males, 3 females)</li> </ul>	<ul style="list-style-type: none"> <li>Community DOTS (TB only) (2 males, 4 females)</li> <li>Community DOTS (TB-HIV co-infection) (2 males, 6 females)</li> </ul>	No FGDs held with patients
<b>Healthcare providers</b>	<ul style="list-style-type: none"> <li>Community DOTS supporters (5 females)</li> </ul>	<ul style="list-style-type: none"> <li>CCWs (1 male, 7 females)</li> <li>NGO staff (3 counsellors, 1 clerk, 1 TB assistant)</li> </ul>	<ul style="list-style-type: none"> <li>CCWs (1 male, 3 females)</li> </ul>
<b>Interviews</b>			
<b>Patients</b>	<ul style="list-style-type: none"> <li>14 (7 males, 7 females)</li> </ul>	<ul style="list-style-type: none"> <li>11 (6 males, 5 females)</li> </ul>	<ul style="list-style-type: none"> <li>11 (7 males, 4 females)</li> </ul>
<b>Healthcare Providers</b>	<ul style="list-style-type: none"> <li>5 (1 male, 4 females)</li> </ul>	<ul style="list-style-type: none"> <li>7 (3 males, 4 females)</li> </ul>	<ul style="list-style-type: none"> <li>6 (females)</li> </ul>
<b>Key informant interviews</b>			
	<ul style="list-style-type: none"> <li>Facility manager</li> <li>Sub-district TB co-ordinator</li> </ul>	<ul style="list-style-type: none"> <li>Facility manager</li> </ul>	<ul style="list-style-type: none"> <li>Facility manager</li> <li>NGO Programme manager</li> </ul>

### ***Non-participant observation***

Observations were conducted by different members of the field team in different areas (e.g. TB waiting room, adherence counselling). Having multiple observers carry out observations

concurrently was necessary for triangulating experiences and reducing individual bias, which can arise when there is only a single observer (Thorogood and Green, 2009).

We initially developed a time and activity flow tool to document and track the movements of individual patients and providers across different spaces in the clinic. The intention was to provide as much detail as possible of their movements in a table, documenting who they interacted with, the nature of their interactions and the time. In practice, this tool and more specifically the table format proved restrictive and limited our ability to capture the detail of the patients (providers) movements and their interactions. We reverted to documenting freely the movements of patients (providers), attempting to capture in detail the content of their interactions. However, since observations were always conducted by two or more persons (principal investigator and a research assistant), it was important that the format of the field notes be standardised. The following structure suggested by Chiseri-Strater and Sunstein (1997, p. 73) was adapted for this study (See Appendix 12 for an example of notes from observations):

1. Date, time, and place of observation
2. Specific facts, numbers, details of what happens at the site
3. Sensory impressions: sights, sounds, textures, smells, taste
4. Specific words, phrases, summaries of conversations, and insider language
6. Questions about people or behaviours at the site for future investigation
7. Page numbers to help keep observations in order.

Upon completion of observations and once the field notes were shared among the field team, a debriefing session was held to allow for reflections on the context, interactions between patients and providers and amongst themselves. Stages 2 and 3 and the data collection tools were revisited and revised accordingly.

### ***FGDs and In-depth interviews***

All patient FGDs and interviews were conducted in the facilities where they received their treatment. In the course of the FGDs and interviews, participants were reluctant to comment negatively on the facility and the healthcare providers. Possible explanations could be that the interviews were conducted in the health facilities and patients did not trust the researchers enough to share openly their views and experiences. Alternate venues (e.g. community centres, libraries) were considered, but these were not feasible for reasons of availability and distance. Participants' reluctance to openly communicate their experiences and opinions raised the question of whether it might be necessary to interview patients twice in order to build trust, but this was not feasible in practice

because of time-constraints, availability of research assistants and loss to follow-up of patients interviewed.

All FGDs were led by a moderator and a research assistant, whose function was to observe and note nonverbal behaviour, group dynamics and emergent themes. FGDs were not conducted in case 3 due to difficulties in recruiting patients arising from the violence in the communities at the time. For details of the composition of the FGDs, regarding treatment (TB or TB/HIV co-infection) and gender, refer to Summary Table 4.2 above.

Various strategies were used for recruiting patients to participate in the FGDs and in-depth interviews. Patients were recruited in the facility with the assistance of facility-based healthcare providers (i.e. nurses, adherence counsellors, doctors). They were also recruited in the community with the assistance of DOTS supporters and CCWs. Community-based recruitment was the key strategy in cases 2 and 3, since patients in these facilities were mainly self-supervised and supported in the community through CCWs.

Given the possibility of loss to follow-up of patients recruited, it was preferable to interview facility-recruited patients on the same day. However, this required patients to remain longer in the facility than they anticipated, contributing to them being tired, hungry and even distracted during the interview. The decision was then taken to schedule interviews on alternate days at the convenience of patients.

Recruitment of patients for interviews was relatively easier compared with FGDs, since the latter required that all participants be available on the same day at the same time. Because of no-shows, FGDs were sometimes rescheduled and patients needed to be followed up. In case 3, because of the high levels of gang-related violence in the surrounding community during the fieldwork, convening FGDs was not feasible.

## **Data entry and analysis procedures**

### ***Data entry***

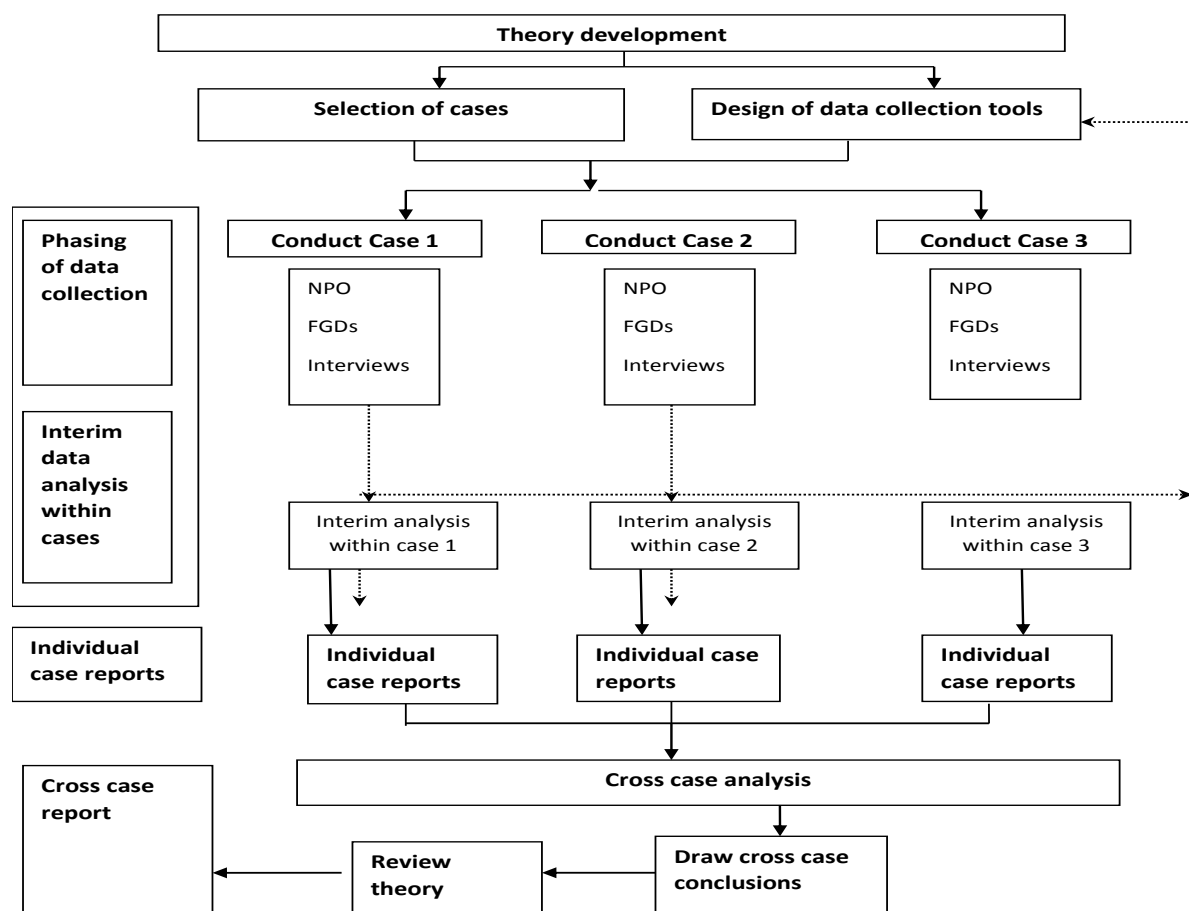
All FGDs and in-depth interviews were audio-taped, transcribed verbatim and translated into English, if conducted in Afrikaans or isiXhosa. Transcriptions were then compared with the recording to ensure accuracy. All observations were written up within a week of them being carried out. Transcriptions of observations and transcripts were uploaded onto ATLAS ti.6 for electronic coding.

### ***Data analysis and procedures***

Figure 4.1 outlines the steps in data analysis. In case-study design, theory development informs the process of case selection and the design of the data collection tools (Yin, 2014). Analysis is an ongoing process and occurs at the individual case level (indicated by interim analysis in Figure 2) and

across cases. As indicated by the dotted feedback line, interim analyses and results from initial cases (i.e. 1 and 2) provides important data against which the content of data collection instruments is reviewed and “redesigned” (ibid, p. 58) if necessary for subsequent cases (i.e. 2 and 3). Data analysis was conducted in two stages; 1) individual case analysis and 2) cross-case synthesis. Interim case analyses resulted in individual case reports, which are not presented in this thesis but are available on request. The findings presented in these case reports were compared and contrasted to support cross case conclusions. In Chapters 6 and 7 of this thesis, I present the cross-case analyses around patient and provider experiences, separately, with specific discussion of the similarities and differences across cases, and consideration of relevant aspects of the initial conceptual framework. In Chapter 8 I then situate these findings against the wider evidence and test the initial conceptual framework. I also propose two new, more detailed frameworks of patient trust in providers and provider trust in patients.

**Figure 4.1: Theory development and data analysis\***



\*Adapted from (Yin, 2014: 50, Figure 2.5).

Data analysis was guided by thematic analysis as outlined by Braun and Clarke (2006, p. 79), who describe thematic analysis as a ‘...method for identifying, analysing and reporting patterns (themes)

within data. It minimally organizes and describes your data set in (rich) detail'. Amongst the strengths of thematic analysis are 'flexibility' (Braun and Clarke, 2006, p. 78) and space for exploring inductive (i.e. bottom-up, data-driven) and deductive (or theoretical, analyst-driven) analyses for especially large amounts of qualitative data. The authors (2006, p. 87) describe several phases or steps in the thematic analysis, which were adapted in this study. These steps comprise: (1) familiarizing yourself with your data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report.

Saldaña (2013) and Miles, Huberman and Saldaña (2014) were drawn on extensively for guidance on the process of coding qualitative data. Saldaña's guidelines for the coding process, including transitioning from coding to the sorting of codes into categories, and synthesis into themes, guided this study's data analysis process.

Below are the data analysis steps:

1. *Familiarization with the data*: reading and re-reading transcriptions, noting down initial ideas. This also included analytical memoing, both during data collection and analysis (Saldaña, 2013). Braun and Clark (2006, p. 202) describe memos '[As] sites of conversation with ourselves about our data'. In this study, these were used as opportunities to reflect on what the research team was observing in the field, interaction with participants, personal or ethical dilemmas, data analysis process, codes and their respective meanings and relationship among codes, categories and themes (Saldaña, 2013).
2. *Generating initial codes*: this required organising the data into groups according to content and meaning. Initial codes or first cycle coding (Saldaña, 2013) were generated inductively (see Appendix 13 for patient and provider code lists). This meant that coding was derived from the data (i.e. transcripts of interviews, FGDs and observations) and not from an *a priori* designed coding list. Codes were a combination of attribute (e.g. provider sex), process (e.g. patient experiencing side-effects), emotion (e.g. provider frustrated by TB policy), values (e.g. patient's expectation that providers treat patients equally), and description (e.g. provider's life history).
3. Transition to second cycle code or more conceptual levels of analysis required reorganising and regrouping the initial codes into 'second-cycle' codes. Saldaña (2013, p. 205) also recommends visualisation of codes, which he refers to as 'tabletop categories' which 'involves the literal spatial arrangements on a table of coded and categorised data' to build sub-categories and categories (see Appendix 14 as an example of tabletop categories). For example, initial codes such as 'provider listening to patient' and 'provider

encouraging/supporting' were subsumed under the second-cycle category 'provider communication style'.

4. Searching for themes (or second cycle coding) is a way of grouping summaries into a smaller number of sets, themes or constructs. This was guided by pattern coding, which Saldana describes as developing 'meta-codes', entailing examining initial codes and categories and identifying trends, patterns, relationships. For example, categories such as 'patient's emotional competency', 'patient's integrity and recognition' were subsumed under the theme 'patient's trustworthiness'. These themes were developed through both inductive and deductive processes. For example, the codes and categories which underlie the theme of 'patient's trustworthiness' were constructed inductively initially from the data (e.g. patient taking responsibility for his health) as well as guided by the literature and conceptual framework (e.g. 'patient's technical competency').
5. *Reviewing themes*: Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis and gathering all data relevant to each potential theme. This was conducted within and across cases.
6. *Defining and naming themes*: Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. Following this, the inductively derived themes were re-examined with respect to the trust and gender conceptual literature.

Alongside the above phases, data displays were developed as an ongoing activity. Miles, Huberman and Saldaña (2014) recommend the use of data display (i.e. narratives, matrices, graphs, tables and various charts) for organizing the assembly of information, building a logical chain of evidence to enable the drawing of conclusions. Matrices are tables based on a 'cross -classification of two or more dimensions, variables, or concepts of relevance to the topic or topics of interest' (Lofland *et al.*, 2006, p. 214). In this study, data matrices were constructed based both on emergent themes (i.e. inductively identified) and derived from the conceptual framework and the research questions (i.e. deductively identified) (see Appendix 15 for illustrative examples).

## **Methodological rigour**

Lincoln and Guba (1985) recommend the criteria of credibility, transferability, dependability and confirmability for demonstrating trustworthiness and rigour within qualitative research. In this study, the application of these criteria and their corresponding strategies are described in this section.

### ***Credibility***

In this study credibility was achieved through prolonged engagement, peer debriefing and member-checking.

#### ***Prolonged engagement***

In case study design, prolonged engagement entails “lengthy and perhaps repeated interviews with respondents, and/or days and weeks of engagement within a case study site” (Gilson *et al.*, 2011, p. 5). In this study, approximately 12 weeks were spent at each facility (see Table 4.2 for summary of data collection). This period of prolonged engagement, which allowed for frequent interactions, was essential for building rapport and trust with the participants (patients and providers) and for reducing reactivity and respondent bias. Reactivity refers to the way in which the researcher’s presence may interfere in some way with the settings which forms the focus of the study (Thorogood and Green, 2009). Respondent bias occurs when respondents withhold or obstruct information or provide information they believe the researcher wants. This period of prolonged engagement in both the facility and community also provided the opportunity for gaining a richer insight into the lived experiences of patients and healthcare providers in the TB setting.

#### ***Peer debriefing***

Peer debriefing was held with different groups. Firstly, through all stages of the research (proposal writing, design of data tools, data collection, analysis and interpretation), the supervisor was the main source for peer debriefing. Secondly, during the stages of data collection, regular meetings were held with the field team to discuss the progress of the research, share perspectives on emerging findings and reflective sessions. Finally, peer debriefing and support was gained through sharing the findings with colleagues. In the initial stages, the draft proposal and data collection tools were shared with colleagues, and revisions and finalisation was made upon feedback. Peer debriefing was also sought with respect to the findings from the case study reports, and cross-case analyses were shared with colleagues in the School of Public Health and Family Medicine. These processes allowed for gaining additional perspectives, as well as for making visible my own biases.

#### ***Member checking***

Participants and specifically healthcare providers were invited to comment on the research findings and themes. The preliminary findings were shared with the healthcare providers from the case facilities. This provided the healthcare providers with an opportunity to validate and correct the interpretations of the investigator. This process was valued by participants, since it provided them with an opportunity for reflecting on how organisational and patient-related factors shaped their experiences. The case reports were reviewed by the sub-district managers.

### ***Transferability***

Transferability refers to the application of the findings to others contexts as a way of achieving a type of external validity (Lincoln and Guba, 1985). A thick description, which entails a detailed description of a phenomenon, allows for the reader to assess whether the findings and conclusions are transferable to other contexts.

In this study, thick descriptions were provided of the multiple contexts (organisational and community) and social relationships in which the cases and participants were situated. In addition, in the findings, quotes using participants' own words and including as much detail as possible of experiences, including beliefs, emotions and context, allows for the reader to evaluate the applicability of the findings to others contexts.

### ***Confirmability and dependability***

Confirmability and dependability was reached through triangulation, a clear audit trail and reflexivity.

### ***Triangulation***

Triangulation via use of different methodological tools, different types or categories of participants and different sites enhances credibility of the study (Lincoln and Guba, 1985).

In this study, there was triangulation by different data collection methods (i.e. non-participant observations, FGDs and interviews), sources of data from different categories of participants (i.e. patients and providers), data collection being conducted by a field team instead of a single investigator, and multiple case studies (or sites). Triangulation was also achieved across field team through conducting observations by more than one field team member of the same areas of focus (e.g. supervision of DOTS, staff meetings) and location (e.g. TB waiting room). Triangulation in data analysis, where patterns of convergence and divergence were identified through the comparison of findings from the different data collection methods and sources of data within and across cases was conducted (Gilson *et al.*, 2011). An example of triangulation of methods of data collection was the finding in case 3 of poor patient-provider interactions between patients who were foreign nationals and providers. This conclusion was drawn based on facility observations and interviews with healthcare providers. Triangulation across multiple sources of data (i.e. patients and healthcare providers) allows for comparing and contrasting accounts of experiences within and across cases.

### ***Audit trail***

An audit trail is understood to be a detailed account of all the research steps from the initial stages of a research project until the final report. (Cohen and Crabtree, 2006). In this study and specifically this chapter, the methodological approach (i.e. research design, sampling, data collection methods



and data analysis) is described in detail. The findings chapter of this study is supported by and carefully indicates through codes, quotes and appropriate citations of data sources (i.e. observations, FGDs and interviews), the sections of the databases containing the evidence that was being drawn upon. This also serves to show that findings reflect participants' experiences and perspectives and not those of the researcher. The use of data matrices (Appendix 15) and tables (see Findings chapters) contributes to building a chain of evidence, supporting the development of individual case and cross-case conclusions.

Finally, all forms and levels of analysis are traceable to each data source through the combined use of ATLAS. Ti.6 (qualitative software) and summary tables (or data matrices).

### *Reflexivity and the role of the researcher*

In this section, I will reflect on my own personal and professional growth, which was shaped by the research topic and methodological approach.

My disciplinary background is in health economics and as a researcher and teacher, my professional life has largely been in an academic setting and specifically a school of public health. The appeal of health economics, and economics more generally as a social science discipline, is that it attempts to understand and extend knowledge of complex human behaviour within a world of increasing inequality and constrained resources, both material and social. More importantly, the appeal of economics from the perspective of social justice and equity is the vexing question of how we as a society allocate resources for the most vulnerable and most in need.

At the same time, as a health economist, I have always been troubled that the underlying axioms of economics, and in particular neo-classical economics, are premised on a number of implausible assumptions (e.g. the economic rational man, maximisation of utility, equilibrium), and that decision-making of individuals and groups can be reduced to mathematical equations, where an individual or group maximise utility subject to a budget constraint. Equally unrealistic and flawed is the notion and practice of predicting group behaviour through an accumulation of the individual's behaviour. This economic view of the world ignores the fact that people are complex beings, where behaviour is shaped by interactions between social (e.g. race, gender, caste) and individual (e.g. physical and mental well-being) factors, all of which are located within a broader political and increasingly globalised context.

Furthermore, in my view, in an attempt to establish economics as an empirical science, the dominant tools of analysis are quantitative approaches (i.e. mathematical and econometric analyses), which I believe are fundamentally inappropriate for investigating and explaining (including

causality) complex social and political systems, including the health system (Gilson *et al.*, 2011). In the words of the late Gavin Mooney, my friend and mentor:

If health economists are genuine in their desire to grapple with equity, they need to recognize more readily that these issues have to be seen through the eyes of potential users and let citizens first include whatever barriers they perceive and second attribute heights to different barriers. To continue the obsession with the **quantifiable** **ill serves the sub-discipline. It serves the disadvantaged even worse** (Mooney, 2009, p. 220) (emphasis added)

The PhD and the focus on relational aspects of human behaviour presented me with an opportunity to step out of the familiar - (i.e. health economics) and a disciplinary perspective which I was, as I have described above, increasingly experienced as limiting - into the relatively unfamiliar. The unfamiliar included alternate disciplinary approaches (e.g. anthropology), research design (e.g. multiple case studies) and qualitative research approaches (e.g. non-participant observations, focus group discussions, in-depth interviews). While the learning curve was steep and often arduous, it was an opportunity for professional and personal growth at multiple levels.

Qualitative research, particularly where one is part of the field team, takes one out of the comfort zone of the academic environment into the 'real world' of the study of interest. 'Being in the field', at the coal face of TB and TB/HIV policy implementation, was an opportunity for unparalleled learning. I had over several years been researching various aspects of TB policy and its implications for patient access in South Africa. In fact, the research questions generated from previous studies on TB, and particularly those relating to the gendered experience of TB patients, contributed to the focus of the present study. However, all engagement with research participants was far removed from the coalface of service delivery. Engagement with research participants was through a database of anonymised respondents, obscuring all that makes the participant unique in personality, experience and history.

This study provided an opportunity for reducing that barrier between myself as a researcher and the research participants, in several ways permitting me to 'see more'. As I was part of the field team, I engaged in all aspects of data collection (i.e. observations, interviews and FGDs) at a facility and community level. This meant that I was able to appreciate participants not merely in their roles as patients and providers within TB service delivery, but more holistically as people with unique stories to share with the world. Moreover, they are, not different from me, rooted in a broader and dynamic network of social relationships often occupying multiple and in many instances competing roles as parents, children, siblings and friends. These roles and relationships are in turn embedded in larger social and political contexts (i.e. gender, race, class, national identity), shaping group and individual values, vulnerability and privileges, which to varying degrees enable or constrain individual's roles as patients and providers.

A key learning was that health facilities remain above all else, people spaces and social institutions. In South Africa, where cultural identity, race, language and ethnic bonds shape our social spaces, group and inter-personal relationships, these also expectedly play out in the health facilities. The discrimination and in many instances denial of services with respect to migrants reflect wider societal discrimination in South Africa. My own identity as a South African of Indian origin of a higher privileged race and social class, combined with my inability to speak isiXhosa, closed off certain social spaces and opportunities for building relationships with many I encountered in the course of fieldwork. At the same time, relationships were also fostered and nurtured through shared values of respect, recognition and trust, cutting across race, gender and professional hierarchy. I had the privilege to witness deep acts of respect, generosity, kindness and what can only be described as love in many of the relationships between providers and patients in the health system. This is very relevant in the current South African context where social divides have widened over the past several years, exacerbated by poverty, inequality and unemployment, which at times feel intractable. This, in combination with low levels of trust in government institutions and fear, challenge the promise of the rainbow nation. Therefore, bearing witness to human relationships characterised by friendship, humour, warmth and, above all else, respect in the health facilities was heartening to witness and be a part of. Affirming relationships built trust and not only enabled co-operation, but for many of the most vulnerable, restored a sense of self-worth, indicating the potential for the health system to play a more powerful transformative role.

The study spanned almost six years, and it is not an exaggeration that the concepts of trust and gender are now the lens through which I now see the world. Trust and gender are concepts which I have internalised and interrogated on a personal level, almost daily, in almost every aspect of my life. What does it mean to trust the teacher of my child? Is it because she (i.e. teacher) is technically competent but also demonstrates kindness, empathy, personal interest in the welfare of my child, is responsive to her needs and vulnerabilities and respects and recognises my needs as a parent? What are the core elements of the workplace that engender trust? Is it an enabling work environment, demonstrations of respect, reward, equality and above all else demonstrations of care and recognition of the individual within the collective? Are female colleagues more trustworthy? What does it mean to trust the research participants? Is it that they demonstrate honesty in sharing their stories and respect in terms of personal and professional boundaries? In the course of fieldwork, there were many instances when my own understandings of trust and gender were tested but provided opportunities for deepening insight into how one cultivates trustworthiness. Box 4.1 below provides an illustrative example through a detailed narrative of how relationships and exchanges with research participants tested and extended by own personal understandings of trust and gender.

### Box 4.1: Personal experience of gender and trust

#### Day 1

Mr Dlamini<sup>9</sup>, the chief professional nurse chatted outside the clinic. His manner is casual, flippant even, he is determined to play the clinic clown. His epaulettes and badges to indicate his rank are never worn and he is often standing outside the clinic smoking. Although we are informed that he is the TB nurse, we seldom see him in the TB section. As we stood outside the facility, chatting in the afternoon sun, he spoke of his wives and children. He described himself as an 'African male, he played hard on the field and off the field.' He said "women don't like men who are not active". He told me about how difficult it was growing up in the dark days of apartheid, losing friends, protesting against the schooling system and crying into one's pillow.

#### Day 2

On the following day, we visited the clinic. Mr Dlamini was standing outside and as we walked passed him on the way to the TB section, he looked Lisa<sup>10</sup> up and down, appraising her and asked "Missy, are you married?" I was furious and responded "Mr Dlamini, she is married and so are you!" We continued walking without looking at him. I had hoped to have embarrassed him and he said nothing to Lisa again until a few days later when he again made some inappropriate remarks. I felt that besides being unprofessional, this was also sexual harassment. It was not until much later that we learnt that he was on the Gender Forum for the sub-district! We chatted about the experience and they (field team) clearly felt uncomfortable and it was important that I raise it with Sr Khumalo, the facility manager which we did. She listened without commenting and then responded that this was not surprising. She had heard of similar challenges with the other male nurse as well. She was infuriated by their defence of it being part of their culture. We met later that afternoon (field team, facility manager, Mr. Dlamini and I). I was wondering how he would react. The atmosphere was calm and I was surprised by the absence of anger and outrage in the room. Instead, there was a feeling of justice and a need to be heard. Lisa spoke emotionally, of feeling objectified and being degraded as a woman. She described the incident as leaving her feeling that she had been reduced to a sexual object and a lack of respect for her as a person. Sr Khumalo was clearly outraged, she reminded him that immediate dismissal was linked to sexual harassment. She asked us what we would like to happen. It was hard, sitting there in judgement of this man and knowing that if he was dismissed, his family would suffer. He apologised for being disrespectful and not respecting the professional and personal boundaries between him and the research team. While the decision was not dismissal, what should be the appropriate 'punishment' for his actions and how would it serve the wider purpose of making him understand how wrong, reprehensible and disrespectful his behaviour was? Although he apologised profusely, I am not sure that he was sincere in his apology or in understanding the gravity of his actions and behaviour.

There were several reflections from this encounter. The 1<sup>st</sup> related to our (i.e. research team) trust in the facility manager to handle the incident discretely and fairly without comprising us. There was a risk that she would not believe us and that could estrange our relationship with her and potentially compromise our fieldwork. However, my expectation was that she would give us and Mr. Dlamini a hearing, that the process would be transparent. By giving us the space to share our feelings, she empowered us and strengthened our respect in her ability to deal effectively and sensitively with a delicate issue. The incident, which exposed our vulnerability and was inherently risky for us, provided an opportunity for building trust with the facility manager.

In addition, I believe by providing a space for my research team to share their experience and concerns and deciding as a collective what was the appropriate response to this issue of sexual harassment, was important for our own relationship as a team. As the principal investigator and their supervisor, it is important that I am trustworthy. By empathising and believing them and allowing them to define the course of action which we mutually agreed on, is not only empowering, but also strengthens our mutual respect for each other and trust in our professional relationship.

My final learning lies in having come full circle on the potential contribution of health economics within health policy and systems research to building a health system that is experienced by all stakeholders as people-centred. The economics of equity is about the just and fair distribution of scarce resources based on need and vulnerability. In contexts of extreme inequity, where vulnerability continues to follow the fault lines of social hierarchies (i.e. race, gender, socio-

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<sup>9</sup> Mr. Dlamini is a pseudonym.

<sup>10</sup> Lisa is a pseudonym.

economic status), resources should be explicitly and carefully targeted to the most *acutely vulnerable* (i.e. vertical equity) be they users of the health system or providers (McIntyre and Gilson, 2000; Govender and Mooney, 2012). Through investing scarce resources in a health system which prioritises the vulnerable, can serve to nurture belief and experience of the health system as a caring institution that is worthy of trust, where for the most vulnerable and marginalised it is safe to be vulnerable. This is critical for the realisation of the vision of people-centred care globally, and the current health reforms in South Africa specifically.

## **Ethical issues**

The research proposal for this study received ethical approval from Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town (See Appendix 1) and City of Cape Town Health Department (See Appendix 2). Access was negotiated with the research facility managers and was described earlier under “Study setting”.

During data collection, posters were displayed across the facilities in all three official languages (Afrikaans, English and isiXhosa) informing staff, participants and visitors that the facility was under observation (Appendix 3).

Informed consent was obtained from all participants in the FGDs and in-depth interviews (see Appendices 4-7). Respondents were informed of the purpose of the research, that participation was entirely voluntary, that they were free to withdraw at any time and that their responses would be treated confidentially. Additionally, for patients, they were informed that there would be no adverse consequences regarding the care they received by refusing to participate. They were informed that all data would only be presented in a way where their anonymity of the respondent would be maintained. All FGDs and interviews were conducted in the home language of the participants. All participants (i.e. patients and providers) received refreshments. In addition, to cover the costs of their time, patients received a voucher to the value of R50.00, which could be encashed at a supermarket retail. All participant names have been anonymised in the thesis.

## **Key limits of the study**

The study has the following limitations that merit attention in further studies. The study was limited to patients who were already accessing care and treatment adherent. Therefore, it excluded those who were not accessing healthcare and non-adherent, and who might have different experiences of trust in providers and the broader institutions of healthcare. The omission of non-adherent patients was a limitation and although the findings may hint at, they cannot claim to comprehensively reflect the experiences of non-adherent patients. Related to this, was the possibility of social desirability bias among participants who were interviewed. Interviews and FGDs held in the health facilities and

patients could have contributed to participants not fully trusting the researchers enough to share openly their views and experiences.

A second limitation related to member checking. While the study findings were shared with healthcare providers in all three cases, this did not occur with patients. Patient feedback was a challenge, since data analysis and preliminary findings were only complete 8-12 months following fieldwork. This meant that many of the patient participants had completed their treatment by this time and logistically, it would have been difficult to recall them for feedback.

## Chapter 5: Overview of context and facility cases

This chapter provides an overview of wider contextual issues that have a bearing on and are relevant for understanding the pathways of influences on patient-provider trust relationships in TB primary care settings. These contextual influences include:

- Magnitude of TB in South Africa (including the Western Cape province and the City of Cape Town) and the emerging epidemic of TB-HIV, co-infections as well as drug-resistant TB
- Health system policy context, including key milestones in South Africa's national TB control policy and the City of Cape Town
- Communities in which research case facilities are located and the influence of social and economic factors which shape the experience of patients and providers
- Features of the research case facilities regarding organization and delivery of TB services which might shape the experience of patients and healthcare providers in the facility, and have a bearing on the facility's performance including key TB indicators.

### **The TB epidemic: a national, provincial and City of Cape Town challenge**

Globally, South Africa is among six countries accounting for 60% of new tuberculosis cases (WHO, 2016a). In South Africa, provinces reporting the highest incidence rates for TB are the Eastern Cape, KwaZulu-Natal and Western Cape, with respective rates of 692, 685 and 681 per 100 000 (Health Systems Trust, 2016). Nationally, Cape Town (Western Cape), eThekweni (KwaZulu-Natal) and Johannesburg (Gauteng) are among the three cities with the highest TB burden (Health Systems Trust, 2016).

The increase in TB incidence has been fuelled by the concomitant HIV epidemic and increasing drug-resistant TB, challenging the detection, management and control of the epidemic, and the country's ability to ultimately achieve global targets for TB control. Globally, South Africa has the highest number of diagnosed drug resistant TB cases (WHO, 2013). This presents a major public health problem, requiring up to 18 months of treatment, with implications for increased treatment and patients costs, which are higher than those for treating conventional TB (Ramma *et al.*, 2015). TB is an opportunistic infection of HIV, and the HIV epidemic has led to a significant increase in the number of TB cases. Besides globally having the highest TB incidence, South Africa now also has the highest TB/HIV co-infection rates. The Department of Health indicates that approximately 73% of active TB cases are also HIV-positive (South African National AIDS Council, 2017), contributing to increasing TB-related mortality.

Nationally, the Western Cape Province, following KwaZulu-Natal, has the second-highest prevalence of TB. The City of Cape Town accounted for more than half of the province's TB burden and almost half of TB patients enrolled for treatment were recorded as co-infected with HIV (City of Cape Town, 2013). While the City has shown an improvement in cure rates (80-83%, between 2009 and 2011) of smear-positive TB cases, in fact higher than most other districts in the country, they still fall short of international targets which are 85% or higher (WHO, 2015c). Against this backdrop of a seemingly spiralling TB epidemic, national and provincial policy and programme efforts to control and manage it will be reviewed in the next section.

## **Health systems TB policy context**

To promote adherence among TB patients in resource-limited settings, the directly observed treatment short course (DOTS) was developed by WHO in 1995 as the recommended strategy for TB control. The strategy then included five key elements: 1) government commitment to sustained tuberculosis control activities; 2) case detection by sputum smear microscopy among symptomatic patients; 3) standardized treatment regimen of 6 to 8 months for at least all confirmed sputum smear positive cases, with DOTS for at least the initial 2 months; 4) regular, uninterrupted supply of all essential anti-tuberculosis drugs; 5) standardized recording and reporting system that allows assessment of treatment (WHO, 1994).

The rise of TB-HIV co-infection and drug-resistant TB in countries such as South Africa, compelled the expansion of the WHO's Global Stop TB Strategy in 2005 (WHO, 2006b, p. 6)<sup>11</sup> to a five point package which includes in addition to the five elements described above: '1) address[ing] TB-HIV, MDR-TB, and the needs of poor and vulnerable populations; 2) contribut[ing] to health system strengthening based on primary health care; 3) engag[ing] all care providers; 4) empower[ing] people with TB, and communities through partnership; and 5 )enable[ing] and promot[ing] research'.

Alongside these global policy developments, there have been several TB policies and programmes in South Africa since 1995 (see Box 5.1).

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<sup>11</sup> WHO's Global Stop TB Strategy was launched in 2005 (2006b) and aims to "reduce dramatically the global burden of TB by 2015 in line with the Millennium Development Goals (MDGs) and the Stop TB Partnership targets". The Partnership Targets, linked to MDG 6, Target 8 include 1) by 2005, detect at least 70% of new sputum smear positive TB cases and cure at least 85% of these cases; 2) by 2015, drastically reduce prevalence and death rates by 50% relative to 1990; and by 2050, eliminate TB as a public health problem.



### Box 5.1 Policy timelines in South Africa's efforts to control TB

**1995:** Revised National Tuberculosis Control Programme (NTCP) based on WHO Directly Observed Short Course (DOTS) strategy replaced the non-standardised short-course chemotherapy (NDoH, 2001).

**1996-2000:** Implementation of DOTS strategy and WHO recommendations focused on the provision of DOTS, improved diagnosis through TB microscopy services, improving TB cure rates (target 80%).

**2000:** Ministers of the 22 'high burden' countries (including South Africa) called for the accelerated expansion of TB control measures, with specific targets of detecting at least 70% of people with infectious TB and curing at least 85% of those detected by 2005.

**2001:** National TB Control Programme's Medium Term Development Plan for 2002–2005. Responding specifically to increasing numbers of TB cases. Objectives by 2005: 1) TB cure rate of 80-85% among sputum smear-positive TB cases detected; 2) detect 70% of estimated new smear-positive TB cases and to achieve DOTS coverage in all districts. (NDoH, 2001)

**2005:** TB declared a national crisis by government and introduction of National TB Crisis Plan

**2006:** The Tuberculosis Strategic Plan for South Africa, 2007-2011 (NDoH, 2006)

**2006:** Development of multidrug-resistant tuberculosis (MDR-TB) and extensively drug-resistant tuberculosis (XDR-TB) action plan

**2011:** National Strategic Plan on HIV, STIs and TB 2012-2016: (SANAC, 2011)

**2011:** Introduction of Xpert MTB/Rif<sup>12</sup> as a replacement for sputum smear microscopy

**2011:** Management of drug-resistant tuberculosis (DR-TB) policy guidelines approved and Decentralised management of MDR-TB introduced.

In 1995, in recognition of the TB epidemic and the major public health challenge it represented, South Africa adopted and implemented country-wide the internationally recommended WHO DOTS strategy. Important milestones in improving treatment access included the rapid expansion of DOTS (100% coverage), the decentralization of TB services, and improvements in ensuring uninterrupted drug supply. Despite these successes, cases continued to rise and in 2005, the TB

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<sup>12</sup> In addition, Xpert MTB/RIF represents a major breakthrough in TB diagnostics and unlike sputum smear microscopy, which has poor sensitivity in HIV-positive people, or sputum culture, which takes three to six weeks to yield basic results and even longer to yield the results of drug susceptibility tests, the new test detects mycobacterium TB and resistance to rifampicin in less than two hours (Churchyard *et al.*, 2014).

cure rate<sup>13</sup> (57.7%) fell significantly short of global targets (85%), National Department of Health (NDoH) compelling government to declare TB a national crisis. They attributed the rising incidence particularly in four provinces (Eastern Cape, Kwazulu Natal, Gauteng and Western Cape) to a combination of factors which included inadequate implementation of the DOTS strategy, increasing number of patients with resistant strains and HIV and AIDS, limited or poor access to laboratories for microscopic services, and migration of TB patients between provinces, among others' (National Department of Health, 2007, p. 10-12). This led to the development of a TB Crisis Management Plan, which focused efforts on the country's four highest TB-burden and poorest treatment outcomes districts, with the objectives of increasing the smear conversion and TB cure rates by more than 10%.

The emergency of TB/HIV co-infection, required that in order to reduce new infections and successfully manage treatment, TB policies and programmes could not be separated from HIV. This was one of the key messages of the Tuberculosis Strategic Plan for South Africa (2007-2011) (National Department of Health, 2007). The plan re-emphasised the 'implementation of the DOTS strategy as a strategic objective in addition to a set of new objectives, addressing TB and HIV, MDR and XDR-TB, health systems strengthening; engaging with a broader range of care providers and communities, empowering people with TB as well as communities and renewed efforts in infection control at facilities. The Plan's targets were: 1) 70% TB case detection rate; 2) 85% TB cure rate; and 2) 85% TB treatment success rate. Unlike the National TB Control Programme's Medium Term Development Plan (2002–2005), which exclusively focused on the biomedical aspects of TB, the Tuberculosis Strategic Plan for South Africa (2007-2011) went further in recognizing the need to address the underlying social determinants of TB, 'An overarching pillar for the elimination of TB is the need to decrease poverty and improve living and working conditions' (National Department of Health, 2007, p. 8).

In order to respond to the dual TB and HIV epidemics and the specific challenge of improving diagnosis and management of TB/HIV co-infection, an integrated National Strategic Plan (NSP) for HIV, STIs and TB (2012-2016) was launched (South African National AIDS Council, 2011).<sup>14</sup> The main goal relating to TB required a 50% reduction in new TB infections and mortality. To be able to successfully reach this target, amongst other recommendations, the Plan called for the integration of TB and HIV services, which through redressing the duplication and separation of TB and HIV

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<sup>13</sup> Cure rate is the percentage of smear-positive patients that were shown to be smear-negative at the end of treatment and at least on one other occasion (each test being at least a month apart), ideally at 2-3 months into treatment; in this instance, TB cure rates relate to new smear positive cases

<sup>14</sup> At a provincial level, provinces (including the Western Cape Department of Health) have also launched their own Strategic Plans for HIV, STIs and TB (Western Cape Department of Health, 2010).

services, would enable access to healthcare services for TB/HIV co-infected individuals. At present, there is no single model for TB/HIV integration, and models range from partially-integrated facilities with on-site testing and referral for treatment to one-stop services for TB patients with HIV and on ARVs. For TB/HIV co-infected patients who need to access both services, the integration of TB/HIV services can address this challenge. Although the NDoH has issued guidelines for the integrating of TB and HIV services at primary healthcare facilities in 2010, 'TB/HIV integration remains poorly implemented and strategies to strengthen integration of services, including ART, are required' (Churchyard, 2013).

## **Organisation and delivery of TB services in the Western Cape Province and City of Cape Town**

The introduction of a District Health Service (DHS) system in South Africa has meant that the responsibility of TB treatment rests with a health district, and services delivery is devolved to primary health care units. Treatment for uncomplicated pulmonary TB is decentralized, provided through primary care facilities, under the administration of either local government or provincial governments.

The responsibility for the provision of health services for the City of Cape Town's almost 4 million residents, lies with City Health (City of Cape Town's Health Directorate) and MDHS (Metro District Health Services (Provincial Government of the Western Cape) across eight health sub-districts. These authorities are also jointly responsible for TB Control Programme activities in the City, and TB diagnostic services are provided by all City and MDHS facilities. However, the delivery of TB treatment is the responsibility of City Health primary level facilities, with support from a range of NGOs. There are approximately 170 City primary care facilities, of which approximately 100 provide TB diagnosis and treatment, and 68 provide treatment only (City of Cape Town, 2013).

Of the City's 170 primary care facilities, 31 provide both TB and ART (City of Cape Town, 2013). While efforts are underway to integrate TB and HIV services at primary care level, and there are a growing number of City facilities providing fully-integrated TB/HIV services, at the time of this study (2012-2016), HIV and TB continue largely to be vertical programmes provided in separate facilities under different health authorities (i.e. City and MDHS), with variations of integrated services including TB-HIV integrated services, and drug-resistant TB provided separately and in some facilities, a higher level of service integration between TB-HIV-drug-resistant TB. In both these instances, TB-HIV and drug-resistant TB are provided separately from other PHC services.

## Profile of study facilities and surrounding communities

This section provides a detailed socio-economic and demographic profile of the communities in which the study facilities were located, followed by a comprehensive description of the study facilities with respect to their administrative and organisational structure and in particular TB services, TB patient load and performance indicators.

### *Location of facilities and communities served*

Table 5.1 below presents a summary of the socio-economic and demographic profile of the communities living and working in the vicinity of the health facilities under study.

**Table 5.1: Profile of communities in vicinity of research facilities**

Facility 1	Facility 2	Facility 3
Coloured township, close to commercial zone, commuter route	Black African township, close to commuter route	Coloured township, close to commercial zone/market areas, public transport hub
Predominantly Coloured and fewer Black African from surrounding communities (middle-working class, informal settlements) and commuters	Almost exclusively African Black from surrounding communities (middle-working class, informal settlements) and migrants from neighbouring provinces	Predominantly Coloured, middle-working class communities; foreign nationals living/working in vicinity of facility
Poverty, unemployment, alcoholism, drug abuse and gang-related violence, violent crime, interpersonal violence	Poverty, unemployment, alcoholism, violent crime, interpersonal violence	Poverty, unemployment, alcoholism, drug abuse and gang-related violence, violent crime, interpersonal violence

Two facilities (Facilities 1 and 3) were located in Coloured townships and the third (Facility 2) in an African Black township. These townships were located in the urban outskirts<sup>15</sup>, between 15-20 kms from the City. They were created between the 1950s and 1970s, following the Group Areas Act<sup>16</sup> in support of separate development, including residence for difference race groups. The community surrounding Facility 1 were predominantly Coloureds and Asian/Indian, representing several well-established working- and upper-middle communities, alongside, in recent years, informal settlements<sup>17</sup>. In comparison, Facility 3 was surrounded by largely low-income working class Coloured communities, living in predominantly council houses built in the 1970s and in back-yard dwellings<sup>18</sup>, the latter a growing phenomenon over the past decade. Unlike Facilities 1 and 3, where Afrikaans was predominantly spoken, Facility's 2 catchment population was mainly African-Black

<sup>15</sup> Townships are now part of the greater metro-City

<sup>16</sup> Group Areas Act involved the forced removal of non-white communities (Black African, Coloured and Asian/Indian) from residential areas located closer to the City

<sup>17</sup> Informal settlements, also referred to as "squatter, informal or spontaneous settlement, a typical shanty town often lacks proper sanitation, safe water supply, electricity, hygienic streets, or other basic human necessities." (Wikipedia)

<sup>18</sup> Backyard dwellings are informal shacks, typically erected by their occupiers in the yards of other properties (Crankshaw *et al.*, 2000)

and isiXhosa speaking. A large proportion of this population lived in informal settlements, many of whom were migrants from the Eastern Cape, driven by rural poverty and relatively poorer employment opportunities, to urban areas.

All three facilities were located close to public transport, which meant that their patient-base was not restricted to the surrounding communities. In addition, facilities 1 and 3 were located close to commercial hubs and the business district and market place. In the vicinity of Facility 3, the market place in particular had in recent years provided employment for Black South Africans and foreign nationals from other parts of Africa, including Somalia and the Congo. Many of these foreign nationals accessed healthcare from Facility 3. Being able to communicate effectively in English or Afrikaans proved to be a challenge for this group of people in accessing health care, including TB diagnosis and treatment. This will be explored in further detail in later chapters.

### ***Challenges of poverty, crime and violence in communities***

High levels of poverty, unemployment, alcoholism and increasingly violent crime characterized communities surrounding all three facilities (See Table 5.1 above). Although drug abuse (specifically *tik*)<sup>19</sup> and gang-related violence was a challenge for communities surrounding facilities 1 and 3, it was particularly striking in Facility 3, in the ways in which it impacted adversely on the mobility and daily lives of both facility staff and patients<sup>20</sup>. Staff discussions were dominated by personal experiences of gang violence and the permanent stress of living in a 'war zone' as it was often described. Staff recounted the challenges of raising families in gang-ridden neighbourhoods and the constant fear that their children would be either co-opted into gangs or lose their lives in the exchange of cross-fire between rival gangs. During the day, it was not unusual to hear the sounds of gun shots as rival gangs exchanged fire in close proximity to the facility. In the course of the study, a young, pregnant woman leaving the facility was shot as rival gangs exchanged cross-fire, despite the fact that the health facility and the incident occurred less than 50 metres from a police station.

In the context of crime and violence, various measures were taken to protect the safety of staff and patients within the facilities. The most severe and extensive measures were taken in Facility 3. The entrance to the facility was controlled by a security gate and patrolled by a security guard. Barbed wire and palisades enclosed the facility's periphery. On one occasion, the security guard was observed escorting a man out of the facility, known to be a regular TB patient, for intimidating and harassing the staff. Concerns over security were also an issue in Facility 2, evident from the

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<sup>19</sup> Crystal methamphetamine is commonly known by its street name "*tik*"

<sup>20</sup> Source: facility observations and patient and provider interviews

palisades surrounding the facility and burglar bars over the windows. The main gate to the clinic remained closed during opening hours except to admit vehicles. Visitors entered through an adjoining pedestrian gate which opened between 7:30 and 8:00 each morning. Aside from these, there were no other security measures (e.g. security guards) in the facility. Patients often spoke of being held up and robbed while waiting for the facility to open in the early hours of the morning. This had implications for their perception of the facility and their overall treatment experience. This will be explored in more detail in a later chapter. In contrast to the other 2 facilities, Facility 1 was striking in the absence of security measures (i.e. security gates, fences, security guards). The entrance to the facility was always open allowing for unrestricted entry and exit of visitors, contributing to a comparatively more relaxed atmosphere.

### ***Profile of facilities***

Table 5.2 below presents a summary profile of the three health facilities in relation to overall size (staff numbers), TB staff composition, support organisations, MDT meetings and security measures.

#### ***Size of facilities***

Facility 1 was the smallest of the three, both regarding staff complement and TB patient load. The City's policy was that since the facility had a staff complement of less than 12 City Health employees, the facility manager and selected staff were required to oversee an additional facility in the sub-district twice a week. On those days, the facility was closed to the community for all services excluding TB.

Facility 2 was the largest facility with more than 30 staff, including a full-time doctor (part-time doctors in Facilities 1 and 3). However, space was a challenge in the facility, given the patient load for all services including TB and HIV. Unlike the other facilities and particularly Facility 3, which was expansive, with large waiting rooms and several vacant consulting rooms, Facility 2 was confined and often over-crowded, with insufficient available seating in the waiting area for patients. During peak times in the mornings, many patients, particularly women and children, would be waiting outside the facility. Lack of space was also a challenge for the staff. While Facilities 1 and 3 had large and adequately equipped staff-rooms (or 'tea-rooms' as referred to by staff), Facility's 2 staff-room was a small prefabricated building adjacent to the facility clinic, which could accommodate at most 10-12 people, although the total number of staff at the time of the research was close to 30. Space was similarly an issue for staff meetings, where meetings were held around the facility manager's office, which could not adequately accommodate the full complement of staff.

**Table 5.2: Summary profile of research sites**

	<b>Facility 1</b>	<b>Facility 2</b>	<b>Facility 3</b>
<b>Sub-district</b>	X	Y	X
<b>Number of staff (City-staff, NGO staff)</b>	10 (City), 3 (NGO)	20 (City), 10 (NGO)	13 (City), 3 (NGO)
<b>Location of TB services in the facility</b>	Same entrance as general visitors Separate waiting area 3 rooms allocated to TB services Sputum booth outside the DOTS room	Separate entrance for TB/HIV patients Separate waiting area 3 rooms allocated for TB services 4 rooms allocated for HIV services Sputum booth outside the DOTS room	Same entrance as general visitors Separate waiting area 3 rooms allocated to TB services Sputum booth outside the TB screening room
<b>TB/HIV Support organisations</b>	2 NGOs	3 NGOs	2 NGOs
<b>TB staff based in facility</b>	Professional nurse, TB assistant, DOTS supporter, part-time doctor	Professional nurse, 2 enrolled nurses, 2 HIV/TB adherence counsellors, TB assistant, CCW supervisor, TB clerk, full-time doctor	Professional nurse, enrolled nurse, HIV/TB adherence counsellor, TB assistant, part-time doctor
<b>Community-based TB staff</b>	5 DOTS supporters	8 Community Care Workers	4 Community Care Workers
<b>Multi-disciplinary team (MDT) meeting</b>	None, but monthly meetings held for DOTS supporters and facility-based TB staff	Yes, included CCWs, adherence counsellors, nurses, TB and ARV clerks, doctor, pharmacy assistant and the CCWs; CCW management absent; initially lead by doctor, afterwards by EN or PN	Yes, included CCWs, adherence counsellors, nurses; CCW management present; lead by EN
<b>Security measures to protect staff and visitors</b>	None	Gated Access facility through pedestrian gate Open during operating hours Facility surrounded by palisades	Gated Access facility through pedestrian gate Open during operating hours Security guard Facility surrounded by palisades Close proximity to police station

### *Services offered*

Consistent with other City Health facilities, all three facilities offered nurse-driven, primary-care, focusing on the provision of preventive and promotive services, which included child health and reproductive and sexual health services, chronic disease prevention and health promotive services, HIV wellness clinics and HAST (HIV/AIDS, STIs and TB) services. With respect to HAST, all City Health facilities, including the three included in this study, provided services for the diagnosis and

treatment of TB and STIs. In addition, all three facilities were involved in out-reach work (health promotion activities including condom distribution, immunization campaigns) and were sites for the dispensing of pre-packaged chronic disease medication.

#### *Organization and delivery of TB services*

Table 5.3 provides a summary of the organisation and delivery of TB services across the three facilities.

#### *TB-HIV integration*

Facilities 1 and 3 offered partially-integrated TB-HIV services (i.e. on-site HIV testing and referral for HIV care), and Facility 2 fully-integrated TB-HIV services (i.e. provided both ART and TB treatment in the same building) (See Table 5.3 above).

In Facilities 1 and 3, diagnosis and treatment of TB was provided alongside a limited range of HIV services. The facilities, like other City Health facilities, offered HIV testing (HCT) and HIV wellness care (pre-ART) and referrals to another facility (often under the MDHS) for ART if indicated. In these two facilities, this operationally meant that all patients presenting symptomatically with TB were also tested for HIV, and all patients presenting for HIV testing to the HCT counsellors were also screened for TB symptomatically, and if suggestive then referred to the TB nurses (professional and/or enrolled nurses) for testing and diagnosis.

Facility 2, which had the highest TB-HIV co-infection rates of the research facilities, represented one of City Health's first fully-integrated TB/ARV sites which intended, through the integration of TB and HIV into a "one stop service", to improve geographic access for people requiring access to ARVs and TB treatment.

#### *Providers of TB services*

Although TB services were primarily the responsibility of the City of Cape Town, the services in all three facilities were supported both in the facility and in the community by a large number of NGO staff coordinated through the City of Cape Town. In Facility 2, the NGO staff outnumbered those of the City staff. City staff included nurses and in Facilities 1 and 3, part-time doctors. NGO staff included a broader range of non-clinical and support staff including community treatment supporters (DOTS supporters in Facility 1 and CCWs in Facilities 2 and 3), HCT/TB adherence counsellors and TB clerks, and a social worker in Facility 2.



**Table 5.3: Organisation and delivery of TB services in research sites**

	Facility 1	Facility 2	Facility 3
<b>Model of TB-HIV integration</b>	Partial integration	Full TB-HIV integration	Partial integration
<b>TB screening approach</b>	Patients presenting at facility with TB symptoms, followed by investigation for TB if symptoms present. No routine contact tracing in home, workplaces, although patients requested to bring young children to the facility for screening	Patients presenting at facility with TB symptoms, followed by investigation for TB if TB symptoms present CCWs during home assessments of TB patients screen other household members for TB and referring them back to the facility	
<b>HCP responsible for screening</b>	Professional nurse, HCT counsellor, TB assistant	Professional and enrolled nurses, HCT counsellors	Professional and enrolled nurse, HCT counsellor
<b>HIV Screening</b>	Patients requesting TB test, offered HIV testing in parallel; patients requesting HIV test also screened for TB symptoms	Investigation for TB if TB symptoms present. Offered HIV testing in parallel. Patients requesting HIV test also screened for TB symptoms, HIV+ patients screened & monitored for TB symptoms	Same as Facility 1
<b>TB diagnosis</b>	Sputum smear, TB culture and chest X-ray	Primarily Xpert MTB/Rif	Xpert MTB/Rif
<b>HCP responsible for diagnosis</b>	Professional nurse	Professional and enrolled nurses	
<b>DOTS during intensive phase</b>	Patients testing TB positive, placed on DOT in facility for 2 weeks of intensive phase, requiring daily visits to facility for duration		
<b>Model of treatment delivery following initial DOTS in facility (DOTS or self-supervision)</b>	<u>Primarily DOT; limited self-supervision.</u> Patient had option of receiving DOT from DOTS supporter, in the workplace, the facility or by a household member	<u>Primarily self-supervision:</u> Patients given 1 month supply of medication and self-supervise. If non-adherent, then facility-DOTS required, where patient takes treatment under observation of healthcare worker (often nurse) in facility	
<b>Adherence counselling</b>	Counselling provided informally by nurse & TB assistant upon treatment initiation	Dedicated lay adherence counsellor provides TB counselling in 3 structured sessions	
<b>Follow-up in community during treatment</b>	Community DOTS patient visit DOTS supporters in their home daily to collect and be observed taking treatment	CCW visits the patient weekly to monitor adherence and conduct pill count	
<b>Follow-up in facility during treatment</b>	For month 2 and month 5 sputum smears; more frequently if smear negative and adherence challenges arising	Monthly for treatment collection for duration of treatment; for month 2 and month 5 sputum smears; more frequently if smear negative and adherence challenges arising	
<b>Involvement of family, friends in treatment plan</b>	Not formal process, but in some instances included as DOTS supporter, typically family member, friend	Formal process; patient required to identifying treatment “buddy” in the initial stages of treatment. Buddy typically family member, friend or neighbour	
<b>Management of non-adherent patients</b>	Referred back to facility doctor, repeat counselling. Managed on facility DOTS or referred for inpatient care for duration of treatment	Referred back to facility, referred to doctor, repeat adherence counselling by counsellor and managed on facility DOTS until adherence is established. In some instances, patients referred for inpatient care for duration of treatment	

Abbreviations: Xpert MTB/RIF: GeneXpert Mycobacterium tuberculosis resistance to rifampicin

In all three facilities, TB services were nurse-driven with doctor support at primary health care. Nurses were primarily responsible for screening, diagnosis and management of treatment of TB patients, and in facilities 2 and 3 these functions were shared between the professional and enrolled nurses. The doctors in Facilities 1 and 3 were responsible for follow-up of TB complicated cases (i.e. side-effects from drugs, sputum is not converting, HIV co-infected patients). In comparison, the doctor in Facility 2 was primarily responsible for ART services. Facility 1 had the smallest TB staff complement with one professional nurse, supported by a facility-based DOTS supporter and TB assistant. All TB screening was conducted primarily by the nurse and to some extent the TB assistant and HCT counsellor. TB assistants were employed in all three facilities and were required to follow-up patients in their homes (i.e. conduct home visits) to recall patients who tested positive for TB and also follow-up on defaulters. These functions were also assigned to the CCWs, and it was unclear how providers navigated these overlaps in their functions.

Facility 2, being a site of full TB-HIV integration, required a broader range of HIV-related staff<sup>21</sup> compared to the other facilities. However, an implementation challenge in relation to patient information and overall monitoring and evaluation of routine information, was the separation and maintenance of TB and ARV patient information (i.e. folders and registries) in different sections of the facility. While TB patient folders were stored and supervised by the enrolled nurses, all HIV folders were stored and managed in the pharmacy by the ARV clerk. The integration appeared to be challenging for communication particularly for co-infected patients. In several instances, providers complained of folders with missing results which challenged their ability to make treatment decisions. All ARVs were dispensed from the pharmacy by the pharmacy assistant, and TB drugs were dispensed by the enrolled nurses from the DOTS TB room. Adherence procedures for patients receiving ART and TB treatment were similar and provided by the three adherence counsellors. The three adherence counsellors rotated between ART, TB treatment and HCT counselling every quarter.

#### *Multidisciplinary Team (MDT) meetings*

TB/HIV integration also required closer interaction between the TB and HIV staff, particularly in the management of co-infected patients. Weekly MDT meetings were held to support this, bringing together the providers from both TB and HIV services (i.e. nurses, clerks, adherence counsellors, doctor, pharmacy assistant and the CCWs). The intention of the meeting was to manage the treatment and intervene when necessary, through the triangulation of information from the clinical staff (nurses, doctor), adherence counsellors and the CCWs in relation to specific individual

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<sup>21</sup> These included an ARV nurse, full-time doctor, ARV clerk, pharmacy assistant and a part-time social worker

patients. The meetings were minuted and were facilitated by either the doctor or one of the nurses. The facility based staff, particularly the nurses and the counsellor, were the most vocal in the meetings, and the CCWs only spoke when they were requested to.

MDT meetings followed an established format. The management of HIV patients was discussed first, followed by TB patients, then dual-infected patients and finally non-adherent patients. For HIV patients in the 'work-up' phase, the home-assessments conducted by the CCWs were presented and the perspective of the adherence counsellors on the patient's readiness to be initiated on ARVs was shared. This would be triangulated with the clinical and laboratory data and a decision would be made as to whether the patient was ready to start ARVs. Interventions were often required when non-adherence, alcohol abuse and failure to return to the facility after a positive test were identified. Interventions included repeated adherence counselling, referral back to the doctor and home visits from the CCWs.

Interestingly, although Facility 3 did not provide integrated TB-HIV services, weekly MDT meetings were held and included the participation of all the TB staff (i.e. City and NGO, including the CCWs programme manager and supervisor, but excluding the doctor). Similar to the MDT meeting held in Facility 2, the focus remained on triangulating information from the HCT counsellor, nursing staff and CCWs on the readiness of patients in the intensive phase to be 'placed out' (i.e. take their treatment under supervision in the community); and interventions necessary for non-adherent patients.

In Facility 1, monthly meetings between the DOTS supporters and TB assistant were held, and in some instances, were attended by the TB nurse. No meetings or other fora for communication between the TB staff and the doctor were observed. The monthly meetings between the DOTS supporters and TB assistant appeared to be initiated and managed by the TB assistant, and appeared to have the following objectives:

- Provide feedback on patients including their treatment from the DOTS supporters
- Handover by the DOTS supporters to the TB assistant of monthly statistics of patients' adherence which were later submitted to the employing NGO
- Remind the DOTS supporters of their patients' sputa dates and provide them with the collection jars
- Share experiences and encourage each other particularly in managing difficult patients.

As noted above, the DOTS supporters kept the patients' green card, which functioned as a daily record of treatment and also a reminder to patients of their sputa dates. The national TB policy required that the card be kept by patients. The responsibility of the DOTS supporters was to

observe on a daily basis patient's treatment doses and record this on the green card. However, in this facility it was found that DOTS supporters held the patients' green cards for the duration of the treatment.

In both Facilities 2 and 3, which were supported by CCWs, one of their tasks included communicating with the patient to return to the facility. Communication was through telephone calls and home visits. A similar practice around TB patient management was observed. During the intensive phase<sup>22</sup>, patients received three rounds of adherence counselling were visited by a CCW for a home assessment<sup>23</sup>, and based on observations from the DOTS staff, a decision would be made regarding whether they were ready to take their medication under community supervision (i.e. be supported by a CCW).

### *TB delivery model*

In all three facilities, TB services including waiting areas were separated from the child health and preventive services. In Facility 2, patients requiring TB and HIV services also entered the health facility through a separate entrance.

All three facilities followed the nationally adopted DOTS TB model for the treatment and diagnosis of TB. These include symptomatic screening, diagnosis through collection of sputum for testing and treatment (Facility 1<sup>24</sup>), and Xpert MTB/RIF in Facilities 2 and 3.

Following diagnosis of TB, patients were recorded and registered at the facility and patients were counselled. In facilities 2 and 3, the process of counselling was formalized over three sessions, and carried out by TB adherence counsellors using flipcharts to support and guide counselling. In contrast, adherence counselling in Facility 1 clinic was carried out informally by both the nurse and TB assistant.

If diagnosed with TB, management of treatment was followed in the following steps:

- Patients were initially observed in the facility for a period of two weeks to test for compliance and side-effects

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<sup>22</sup> Discussion of TB patients' preparation and readiness for placement out (i.e. following two weeks of observation and daily DOTS in the clinic, patients can be placed out in the community for treatment under the observation of a CCW).

<sup>23</sup> Typically, the CCWs give feedback on the home situation of the patient, and include information on whether the patient had disclosed to a household member, whether they had a treatment buddy/supporter, their smoking and drinking habits, and whether there were children (under five contacts) in the home.

<sup>24</sup> In 2011, SA introduced Xpert MTB/RIF as a replacement for sputum smear microscopy for the diagnosis of pulmonary TB, and the introduction was implemented in phased approach. In Facility 1, at the time of the study in 2012, Xpert MTB/RIF had not as yet replaced sputum smear microscopy

- Decision was made as to whether the patients would be on facility DOTS; community DOTS under supervision by a DOTS supporter (Facility 1) or CCWs (Facilities 2 and 3); in the workplace; and finally under self-supervision (Facilities 2 and 3). At the time of the study, there were no patients on workplace DOTS in Facility 1 and a limited number in Facilities 2 and 3.

During treatment for new smear positive cases, patients were required to provide sputum twice during the course of the six months' treatment, to test if the treatment was effective in reducing the bacillary load in sputum; first between 2-3 months and second at five months, close to the end of treatment. In facilities 2 and 3, when poor adherence and any side-effects from the regime were identified and successfully treated, management of treatment in the continuation phase was primarily through self-supervision, where patients were given one month's supply of medication and were visited weekly by the CCWs. The CCWs had a broad range of functions which included conducting home assessments of patient's pre-treatment and during treatment, checking the patient-held green card for recording doses taken, reminding patients to collect their monthly medication and bring their sputa to the clinic for testing, and motivating patients to complete their treatment.

In Facility 1, as noted above, there was limited self-supervision, and patients' treatment in the continuation phase was managed primarily through community-DOTS, where patients visited daily DOTS supporters in their homes to collect and be observed taking treatment. Many of those who remained on facility DOTS were from the informal settlements, primarily because of the lack of availability of DOTS supporters in the settlements.

The DOTS supporters, like the CCWs, were attached to the facility and were responsible for monitoring treatment adherence. They were assigned patients who lived in close proximity to themselves and, like the CCWs, their roles also extended to motivating patients to complete their treatment, reminding them of their follow-up tests in the facility. The DOTS supporters were also responsible for following patients who were non-adherent. Unlike patients who were under self-supervision, all medication was held by the DOTS supporter. They would return to the facility to restock. These visits often coincided with their monthly meetings and also provided an opportunity to report any problems they may have encountered. In the periods intervening. The TB assistant also followed-up with the DOTS supporters in the community to check on patients and identify any challenges that they were experiencing.

#### *Key facility and TB statistics*

Table 5.4 below indicates relevant facility statistics (headcount, TB case finding, MDR case load and TB-HIV co-infection) and performance indicators (cure rates and percentage defaulting) for the

period 2012-2014. Facility 2 was the largest of the three facilities, both regarding overall facility patient load and the TB DOTS population. Importantly, although Facility 2 also had the highest HIV-TB co-infection burden, its MDR case load was comparable with facility 3.

With respect to the TB programme, the percentage of patients on facility DOTS declined significantly over the three years, most markedly in Facility 1 (58% in 2012 to 0.5% in 2014). However, Facilities 2 and 3 continued to have a significant proportion of their patients on facility DOTS (30% in Facility 2 and 17% in Facility 3 in 2014), on account of the higher drug-resistant TB burden in both facilities. By 2014, all facilities had met the TB cure rate target of 85%. Interestingly, although Facility 2's cure rates exceeded the targets for all three years, the cure rates were on a downward trend. The reverse was observed in Facility 3.

**Table 5.4: Facility statistics for TB performance indicators (2012-2014)**

TB indicators	Facility 1			Facility 2			Facility 3		
	2012	2013	2014	2012	2013	2014	2012	2013	2014
Facility headcount (F3); Pt load (F1, F2)	14571	11590	17073	37942	37099	52893	48821	45920	48994
TB case finding	269	223	218	503	428	404	431	401	356
New smear + PTB (%)	25.3	24.2	19.3	22.9	23.1	19.8	26.5	22.4	27.5
New smear + cured (%)	85	80	85	89	88	87	80.7	81.1	87.8
New smear + defaulted (%)	10	13	9	3	3	6	10.5	12.2	7.1
MDR case load	5	12	11	22	17	13	19	15	25
DOTS population	248	221	217	503	428	404	424	361	354
% on facility DOT	58	17	0.5	29	30	19	42	16	17
TB / HIV	59	52	48	282	233	216	57	41	59

## Concluding remarks

This chapter has provided a rich and detailed discussion of how South African context (social, economic and historical) at personal, community and health facility level might have a bearing on trust and gender in patient-provider relationships. These relationships are situated within a macro context of South African health policy, where numerous policies which have a bearing on the organisation of health services, can in turn influence patient access and relationships of trust.

*I found there is care in this clinic ... When I arrive here I found the nurses are always happy and full of joy ... the staff is treating me very well ... it makes me feel to be encouraged. [P1, male, Facility 1]*

## **Chapter 6: Influences on patient treatment adherence and building blocks of patient trust in providers**

In this chapter, patients' personal experiences of TB and the ways in which these impact on them personally will initially be explored. The implications for their specific needs, vulnerabilities and expectations, which in turn influence how trust is built and experienced with respect to providers and the health system, is examined. The chapter presents a cross-case analysis<sup>25</sup> of the data with respect to the following questions:

1. What influences patients' treatment experience and adherence?
2. Are there differences between men and women regarding experience and adherence?
3. What is the influence of providers' gender on patient treatment experience?
4. What are the building blocks of interpersonal and institutional trust?
5. Do men and women construct interpersonal and institutional trust differently and if yes, in what ways?
6. What are the outcomes of trust in providers and the institutions?

As noted in the methods chapter, all participant names have been anonymised. All participants referred to in this chapter are described by participant number (e.g. P1, P2 etc.), sex (i.e. male, female) and facility location (i.e. Facility 1, Facility 2, Facility 3).

### **What influences patient experience and what are the challenges for adherence?**

Patients were predominantly Coloured and Black African and either lived in the vicinity of the health facility or a neighbouring community. Most participants had lived in Cape Town over an extended period of time, while some were migrants having left their families in the Eastern Cape, or from neighbouring countries having relocated with their families.

This section describes and examines from the patient's perspective, influences on their treatment experiences with implications for adherence. In interviews and FGDs, patients were asked directly about aspects of their personal lives, the treatment itself, relationships with providers and

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<sup>25</sup> The findings presented in this chapter are derived from the cross-case analyses of the individual cases. Full case reports for each case were prepared; these are not presented here but available for review.

organisation of the services, which made them vulnerable and affected their ability to take and complete their treatment (see Appendices 8 and 9). Their responses were coded and subsequently categorised into three broad categories or levels; personal, community and health service (see Table 6.1 below). These levels are informed by the typology advanced by Sabaté (2003), described in Table 2.3. Across all facilities, patients consistently identified the same factors and vulnerabilities as having a bearing on their ability to adhere to treatment. The only exception related to community safety, which was raised as a challenge in Facilities 2 and 3 (and not Facility 1). The challenge of violence and crime as important influences on treatment adherence in Facilities 2 and 3 was also supported by the non-participant observations (see Chapter 5, ‘Challenges of poverty, crime and violence in communities’).

**Table 6.1 Influences on patients’ treatment experience and adherence**

Influences on treatment adherence	Facility 1	Facility 2	Facility 3
<b>Personal level</b>			
Motivation to live	✓	✓	✓
Socio-economic and psycho-social challenges	✓	✓	✓
Competing priorities of work, household roles and treatment	✓	✓	✓
Lack of social support	✓	✓	✓
Drug dependency	✓	✓	✓
TB/HIV co-infection	✓	✓	✓
<b>Community level</b>			
Unsafe community	-	✓	✓
Stigma	✓	✓	✓
<b>Health service level</b>			
Side-effects of treatment	✓	✓	✓
DOTS model of treatment	✓	✓	✓
Facility timings and waiting time	✓	✓	✓
Provider attitudes and behaviour	✓	✓	✓
Providers know their jobs	✓	✓	✓

Key: ✓ indicates that the factor was identified by participants (i.e. patients) as an influence on treatment adherence. These influences could be either positive or negative, impacting either positively and encouraging adherence or negative and discouraging adherence.

### ***Individual level***

#### ***Motivation to live***

All patients expressed a strong sense of commitment to completing their treatment, driven by a range of reasons. Almost all spoke of the need to be healthy again and resume their earlier way of life, including household, childcare and work responsibilities. TB also impacted on participants’ ability to fulfil household, including parental responsibilities:



And now mommy is just lying there, daddy must do breakfast, daddy must make food (laughing) ...It [TB] made me feel very weak, it made me feel unpleasant because these are the things that the woman should do in the house. [P8, female, Facility 1]

The fear of death particularly for those with young families was a motivation for male and female participants to adhere to treatment:

What's happening in my community if there's gangsters killing themselves, look I can pray for them, but I'm not gonna let that pull me down, because I've, I've got a vision I know where I'm going to, I need to do this because it's good for me it's good for my kids ... [P4, female, Facility 3].

My motivation to take my treatment is my children ... I have a boy who is 1 year 8 months whom I want to see him growing old, to see him reaching a certain stage ... This child must be able to point at me and say "There is my father. I am now going to the initiation school, my father will be there for me." That is what motivates me, you understand. [male, FGD TB adherent, Facility 2]

At the same time, TB infection in some instances was rationalised as a 'gift', an opportunity for a second chance at turning one's life around:

TB cut off a lot of things from me ... TB actually made me realise to pull the breaks you see, but before that I was happy go lucky ... I loved smoking buttons and smoking cigarettes. I smoked two packs up in one day; those are the things that I really miss you see ... and I just left it like that ... I don't smoke buttons, they [friends] don't come to me anymore. It doesn't bother me ... They [friends] did me a favour because I have more quality time with my children ... I have a very sweet daughter and a boy he is six years old she is two ... [P9, male, Facility 3]

Despite being motivated and committed to their treatment, there were a range of factors which challenged their treatment access and adherence.

### *Socio-economic and psycho-social challenges*

Almost all patients across facilities could be described as socio-economically poor, many of them were either unemployed or engaged in serial temporary jobs (or referred to by many as "piece-work"), dependent on social grants. In addition, many of them lived under tenuous living arrangements. They often described lives characterised by multiple and co-existing material (i.e. unemployment, hunger, poverty) and psycho-social (i.e. migrant status, emotional distress, social connectedness and social status) vulnerabilities which influenced their treatment experience, and in some instances challenged their ability to adhere to treatment. Living conditions varied among patients. Some described living in formal homes (i.e. brick and mortar homes). Others described more desperate living conditions, ranging from informal settlements to 'backyard dwellers', the latter referring to people living in unstable, temporary structures:

I am not staying in a house like other people. I am staying in a small little wendy house and there is a lot of air, lot of holes where the wind and stuff comes through and the rain. [P10, female, Facility 1]

For those affected by multiple material vulnerabilities, TB also meant that they were confronted by the vicious cycle of TB - loss of work - poverty, where their illness prevented them from working or even seeking work, leading to a deepening cycle of poverty and socio-economic vulnerability. Many patients (both men and women) who were unemployed, reported struggling on a daily basis to support themselves and their families, and hunger remained a challenge for many and in some instances challenged treatment for adherence:

I'm not even sure if I'm going to have something to eat tonight um ... how can I go and take that medication and I've got nothing to eat? (P4, female, Facility 3)

### *Competing priorities of work, household roles and treatment*

Poverty meant that they continued searching for work even when they ill. While some felt it safe to disclose to their employers about their ill-health, others lied in order to protect their employment and income:

I said "Listen Boss, I can't make it for 4 weeks" and he asked me "Why?" I told him "Listen here man I got a funeral to arrange now man but I will come again to you Boss". I thought hey he is going to fire me now on the spot. The Boss said to me "Listen here, I don't want that problem again" and I said "No, Boss I won't give you that problem again." [P9, male, Facility 1]

For working participants, the practical aspects of treatment (i.e. daily visits to the facility under DOTS in the intensive phase, treatment collection and waiting time) had implications for their ability to work, requiring empathy and flexibility from the healthcare providers to accommodate patients' needs beyond the immediate therapy. This will be examined in a later section.

### *Lack of social support*

All participants spoke of the role of social support in coping with the disease and remaining adherent. While most participants (male and female) appeared to have access to stable and reliable forms of social support (e.g. partners, friends, family), migrants, particularly men, were unable to draw on similar support systems, contributing to social isolation and estrangement. This is illustrated in the contrasting patient experiences in the following quotes:

My life has changed for the worst really because I left my family in the Eastern Cape ... I used to be a very happy person but now I am always thinking that I left my family in poverty ... the only help they [brothers] have managed to give me is to put me in their shack so that I don't sleep outside ... [P6, male, Facility 2]

When you are having this TB treatment you can't cook for yourself, you can't do anything, and then that time he [husband] had taken a leave and then my mother-in-law had to come from Zimbabwe and then my other sister, because they had to take turns ... my husband used to encourage me ... my mother-in-law she used to be a nurse there in Zimbabwe ... so she made sure in the morning she cooks for me like some cereals, she made sure I take my medication you know. [P19, female, Facility 1]

### ***Drug dependency***

As described earlier, drug dependency was particularly a challenge for communities surrounding Facilities 1 and 3. Expectedly, several patients in both these facilities spoke of the challenges of drug dependency and ways in which it affected their lives. Many of them described lives of unemployment and drugs as a way of life, contributing to a sense of hopelessness. A 49-year-old male participant, unemployed, with a family of four, dependent on social grants, described his challenge with drugs:

I did a lot of drugs, smoked with different people out of the same [pipe] ... that is where I picked up the TB ... Friends gone, it doesn't exist anymore, believe me I don't smoke buttons. They [friends] don't come to me anymore, it doesn't bother me. [P4, male, Facility 3]

In Facility 1, an unemployed man, who earned a living through piece-work, had a history of drug dependency. He described his daughter's dependency on *tik*, which drove her to steal from him:

My daughter stole my clothes and I don't let her in because my best clothes disappear and she is on tik ... She just steal clothes; she stole all my best pants and go sell for a tik...I told my brother "No, let she stays away and I am not going to let her in". So, if I locked the gate I am not going to open it again for her because she steals and I don't steal. [P14, male, Facility 1]

### ***TB-HIV co-infection***

For co-infected patients, the regimen's pill burden, dosing frequency and experience of side-effects was an important challenge which often discouraged them from adhering. This was further complicated by their material and social vulnerability, as evident from the following CCW's home visit to a male patient who was dual-infected:

His house is obviously poorer, and less cared for. His wife recently died, and relatives took his daughter to the Eastern Cape. His pill bag is filled with empty bottles, which the CCW says he must destroy, since it is making things too confusing. The CCW explains carefully when he must take the TB tablets, and when he must take the ARVs. She later explains to me that he does not follow the protocol and takes his tablets at any time of the day, instead of in the morning and at night. [Community observations, 15 May, 2013, Facility 2]

### ***Community level***

#### ***Unsafe communities***

While crime and violence associated with living in working class and informal settlements was a recurring theme featuring in many of the participants' narratives across the facilities, it was particularly a challenge for those in Facilities 2 and 3.

I met some boys here in [name of place] on my way from my piece jobs that I get sometimes. The first one came and grabbed a packet of chips out of my hands and the other four were still coming ... I was stabbed on the back three times ... the following day I was stitched ... [P5, male, Facility 2]

For participants living in the vicinity of Facility 2, the challenge of gangs, and the associated violence, affected the daily lives of almost all the patients in one way or the other. For some, gang violence obstructed access to their closest facility, and they were forced to seek care from the research facility because the access route to it was relatively safer. For others, the facility was their closest and only option, although fear of being caught in the cross-fire was constant:

Violence in community is a lot ... the devil is loose in that [community]. People are being killed every day on the road that we have to go through ... [P1, female, Facility 3]

Another young man with three children, who was a member of a gang, felt it unsafe to take his treatment at the facility closest to him since he could be attacked by his “enemies” (i.e. rival gangs):

I have been in a gang for many years ... that side are our enemies. Things started getting out of hand and it made me not to be able to go to the clinic [previous facility]; okay this side [current facility] there is also [rival gangs] but I just take a taxi and drive past them ... [P5, male, Facility 3]

For patients such as those described above, who faced the challenge of seeking treatment which meant risk of being harmed, raised expectations of ways in which the facility and the providers could accommodate these challenges.

### *Stigma*

Participants, both men and women, Coloured and Black African, across all three facilities spoke of the challenges of stigma and community norms which influenced their illness and treatment experiences:

They say to you “put your hand before your mouth” ... they remind you that you have TB and you can’t stand with them or talk to them. Then you think about it and relate it to them and say “I am taking my medicine.” Even the people in your work place they will say to you “no, drink in your own cup, eat your own bread”. That makes you feel like they don’t accept you as a people, as human ... they reject you because you are sick ... they don’t want to do anything with you ... They make you feel inferior to them, yes. [P6, male, Facility 1]

I have a problem with my neighbours. My neighbours are insulting me for being HIV ... they are judging my children in the community. My children are unable to play with anyone ... They are judging me and compare me with everything including dogs that have shed hair. They say dogs have shed hair just like me ... [crying] [female, FGD, Facility 2].

In both instances, TB meant social isolation and, worse in the second case, exclusion of the participant’s children from the community. In addition, in many communities where there is growing TB-HIV co-infection (second quote above), TB is increasingly being perceived and experienced as a potential indicator for HIV-infection.

As evident above, both men and women identified stigma, operating within their communities and social networks as alienating. Interestingly, only men spoke of the problem of presenting as a male in a facility as a barrier for seeking care. This was observed across all three facilities:

The first time I heard I got TB I said “Hey, what will the ladies say about me, I got TB”. I look after nice ladies mos. I asked doctor “Doctor! Is it a matter of scariness or what?” and the doctor said “No, everybody got TB, you don’t have to be scared, you don’t have to be scared because everybody got TB”. I said to him “Oh! Everybody got TB?”. So I got used to it man. I come and I sit with ladies here, you saw the one who was sitting here, the last time I come here she was sitting and she is a nice girl. She is also got TB and we talk nicely man. She agrees with me and she was also scared the first time like me. But now I am not scared anymore. [P9, male, Facility 1]

It doesn’t make me feel good. Because now everyone is looking at me. You come and the majority are just women. “What is this man doing here? What is he here for? He is here every day?” But they also know what you are coming for. [P3, male, Facility 3].

### ***Health service level***

#### ***Side effects of treatment***

Almost all participants, particularly dual-infected, described their experiences with side-effects. Side-effects included nausea, orange-coloured urine, dizziness, itchy skin, rashes, diarrhoea and nightmares:

Nausea that I picked up it’s terrible I’m always nauseous; and this thing I don’t know what is it, that is growing on my lip and it’s from when I started getting treatment. [Okay, now did you mention it to the Sisters?] Not yet I haven’t mentioned it to them. I keep forgetting to ask them about this there are times I just want to get away ... [P 9, male, Facility 3].

In Facility 2, dual-infected participants cited, in addition to side-effects, pill burden as being an important influence on their ability to adhere to treatment, particularly in the initial stages. At the same time, despite it being a significant challenge for this group of participants, they remained committed to their treatment:

When I started these TB, I was also taking ARVs, I couldn’t cope, no, the pills were too many. I had to chase 20 [tablets] ... so I realised they are too many ... now they are better and I am used to them, because it was difficult to even swallow them because they were too many. In the end, I want to live and I do not want me to stay in that bed and blame myself for not completing my TB treatment. [female, FGD, Facility 2]

#### ***DOT model of treatment***

As described earlier, the facilities followed relatively similar approaches to the implementation of DOTS. All facilities had progressively over the years reduced the proportion of patients under facility DOT, and increased the size of community DOT and self-supervision, with the introduction and replacement of DOT supporters by CCWs. Therefore, while DOT was applied for the entire treatment

process, increasingly the daily clinic-based DOT approach was limited to those described as chronic defaulters or drug-resistant TB.

For all other patients, a more flexible approach was evident where patients were supervised in the community or workplace and in some instances, supervised by a family member, and they were also required to attend the clinic either weekly or monthly to collect the supply of drugs. Participants were only 'placed out' once they had proven their commitment over a period of two weeks of observation during the intensive phase:

Look they [providers] don't give you much of a choice. I ask questions, I gave them options, alternatives, "Can't I get the two weeks supply?" Their rule, what they say to you if you want to get better, "You do it our way you have to be here every single day. Bottom line and after that two weeks if we see you coming in regularly then you can get that months' supply". So in that two weeks, show them how committed you are. So should you default within that two weeks meaning that the month after, you not gonna get your tablets, you're monthly supply you will be coming in each and every morning but I think in terms of inconvenience ... [P4, female, Facility 3]

As will be discussed later, most participants were less favourable towards facility DOTS compared to community DOTS given the associated time and transport costs. Surprisingly, in Facility 1, several participants supported facility over community DOTS. For this group of participants, besides ensuring that they took their treatment, DOTS also served to demonstrate their reliability and commitment to the healthcare providers (demonstration of patients' trustworthiness to the provider):

For me was easy to come here every day, because my child was also TB, so I needed to come with him and for me also. They [providers] wanted to give me my tablets to drink there at home. I said, "No, if I drink there, I would get lazy to come here to the clinic and if the tablets finish I will say no", so I used to come every day, even it is raining, I come. I choose to come, every day, 'cause so I can't get lazy. [female, FGD, Facility 1].

This finding needs to be explored within the context of the availability and reliability of DOTS supporters in Facility 1. To recap, under the community DOTS model, for the full duration of treatment (i.e. six weeks of intensive phase and six months in the continuation phase), patients were required to visit daily the DOTS supporter that they were assigned to and take their treatment under observation. When DOTS supporters were unavailable to their patients, this challenged adherence. In the following extract, there were no DOTS supporters available to support patients in an informal settlement, and the participant described being demotivated to travel daily to collect her treatment from the facility:

It is too far to walk, actually, not too far, I can walk but when I am walking then I am getting tired, then I must first stand for a moment then I must walk again. There was a DOTS supporter, but only for two months and after

that then she don't want to work again, I don't know what happened. She was a fine girl and she was very nice ...  
I did get lazy [to visit the facility to collect treatment], and if it is raining, and hot ... [P2, female, Facility 1]

In other instances, despite DOTS supporters being located in the vicinity of their homes, participants argued that the DOTS supporters were absent when they visited to collect their treatment, once again raising a challenge for treatment adherence. This will be discussed further in a later section exploring the implications of this for the reliability and hence trustworthiness of providers.

### *Facility timings and waiting time*

Many participants indicated that their personal responsibilities which included household and employment-related responsibilities (i.e. continuing to work or searching for work) and in some instances attending school, made it difficult for them to receive their treatment at the facility:

People have to be at work at 8 or 9 o'clock. You cannot come here and sit and wait till 10 or 11. That can de-motivate the patient to come and get their medication. I've got two options, it's either I'm gonna lose my job; or I'm gonna come here. I got a warning, the owner knew I had to be on treatment. I still had to sign a written warning because I open[ed] his shop late ... [P4, female, Facility 3]

As will be explored later in a later section, the extent to which facility timings and waiting times met patients' expectations, and the extent to which patients perceived that these were rooted in factors outside the providers' control (e.g. provider shortages in facilities 1 and 3), or in unprofessional and uncaring attitudes and behaviour on the part of providers, had implications for their trust in providers and the institution.

Patients' experiences and their adherence were also influenced by their experiences of technical competency (i.e. know what they are doing) and interpersonal communication (attitudes and behaviour). Assessments of providers against these two dimensions had implications for patients' assessments of their trustworthiness.

### *Provider attitudes and behaviour*

Attitudes and behaviour, both verbal and non-verbal, that demonstrated care, respect and empathy on the part of the providers, was a recurring theme for both male and female patients across all facilities. Both community-based (i.e. DOTS supporters and CCWs) and facility-based staff was largely experienced as encouraging and supportive:

She is a lovely Sister [CCW] ... If she came to the house, we have good relations. She helps me ... It is not just about my pills, she also chats with me. [P8, male, Facility 3]

Further, when patients believed that providers trusted them, this was a motivator for treatment adherence:

The sister asked if I was going to be responsible enough to take it [treatment] by myself. I said yes ... she trusted me ... that also motivated you a lot because if you feel or let's say you see they are trusting you, I am not going to prove them wrong or anything. [P11, female, Facility 1]

They trust me and they can see on the files, on my X-rays, it's TB is disappearing. I am still five months under the medication now ... I noticed it is not every patient that they trusted. They must come and drink their tablets here every day. For me, no I take my tablets home because I got people at home, my sister-in-law who signs my card. They [providers] got her phone number ... I had to give them her phone number and this is how it works. [P14, male, Facility 1]

As will be highlighted in the discussion, being perceived as trustworthy not only motivates patient treatment commitment and adherence, it can also potentially improve the quality of the patient-provider relationship regarding cooperation and participation.

The importance of being recognized, often signaled by being addressed by one's first name, was important for several patients. In addition, in some instances, there was a familiarity between providers and patients, suggested by patients referring to the providers, particularly the CCWs, by their first names, and patients being observed addressing some providers as "aunty". In contrast, poor communication styles were more often associated with facility-based staff, who were judged as being in a hurry, discouraging participants from sharing and disclosing what was important for them:

They treat us like we are children. We are not children ... Being a child ends there to your mother and father ... It seems we are stupid, and they treat us as if we have half brains ... You [patient] even become afraid to disclose other problems. This person [facility-based provider] comes in in a hurry ... I cannot tell him what I was supposed to tell because he is in a hurry. I do not know why he is in a hurry because she has arrived at work. [female, FGD, Facility 2]

The environment is okay, but when you have to see the doctor, it's in and out, in and out, even when you want to talk to the doctor about what you want to talk about. [P3, male, Facility 3]

### *Providers know their jobs*

Assessments of providers' technical and professional competencies were based on demonstrations of providers "knowing what they are doing" and "giving of their best":

The way they do things tells me they know what they are doing ... [P9, male, Facility 3]

In addition, ways in which providers communicated and demonstrated confidence in their own abilities, had implications for patients' judgement and confidence that the provider was competent to meet their health care needs. This is illustrated in the contrasting patient experiences in the following quotes:

The first time she [professional nurse] did my folder it took a long time, because she was saying she was still learning about the TB thing and something like that. Sometimes you start now to lose confidence in the nurse, is this person know what she doing or, or what? I didn't say anything, I was just quiet because you sometimes you



get afraid, because at first I was having the wrong medicine, then you know she's not knowing what she's doing ... [P19, female, Facility 1]

She [adherence counsellor] explained everything to me and even showed me a book and said "Do you see how TB is, it does this and this to your lungs", thereafter I knew what it was. [P1, male, Facility 2]

## Are there differences between men and women regarding experience and adherence?

Patient experiences were also examined to consider similarities and points of difference by gender (summarised in Table 6.2 below). This table also indicates whether factors were experienced as positive and enabling (+) or negative and challenging (-) for treatment adherence.

A clear message emerging from the analysis of data in the study is that men and women often experienced in similar ways individual (e.g. importance of social support and motivation), community (e.g. stigma and crime) and health service (e.g. distance from facility, DOTS) level factors as influences on their treatment experience and adherence. However, in some instances, the underlying reasons differed. For instance, although both men and women who were co-infected with TB and HIV identified the pill-burden as a challenge for adherence, some men were further disadvantaged by the absence of social support.

In addition, there were some challenges that were experienced by either men or women alone. Unique influences for women included, at an individual level, responsibility as a parent or household head as a motivation to commit to treatment. In addition, at a health service level experiences with other services (e.g. family planning, child health) were identified as having a bearing on women's experience. On the other hand, men differed from women in a number of ways at all three levels. At the individual level, poverty, unemployment, absence of social, and alcohol and drug dependency were significant challenges. At the community level, for some men, the challenge of gang involvement was raised. At the health service level, unique challenges for men included the stigma of being a male in a health facility, and pill burden coupled with lack of social support. The challenge of masculinity as a source of vulnerability for treatment access and adherence is addressed in the discussion chapter with specific recommendations in the conclusion.

**Table 6.2: Summary of gender-related influences on patient experience and treatment adherence**

	Similarities between men and women	Differences between men and women
Individual level		
Poverty	Both men and women cited poverty and hunger as a challenge for adherence (-)	More men who were unemployed or undertaking piece-work spoke of poverty and being dependent on others for food and shelter (-)

Unemployment	Both men and women cited the challenge of loss of work and income a challenge for adherence (-)	More men cited the challenge of being unemployed and time taken for looking for work as a challenge for adherence (-)
Social support	Both men and women spoke of the importance of family/friends support for enabling treatment adherence (+)	More men spoke of the absence of support from family and friends support as a challenge for adherence (-)
Drug/alcohol dependency	None	More men than women spoke of the challenge of being drug and/or alcohol dependent as a challenge for adherence (-)
Physical distance to facility	Both men and women sited distances from home to facility as a challenge, particularly for daily DOTS (-)	No differences between men and women
Motivation to commit to treatment	Both men and women spoke of committing to treatment to be healthy and 'have their lives back again' as enabling adherence (+)	More women spoke of the motivation to commit to treatment because of family/children (+); more men spoke of committing to treatment because of employment/employment seeking (+)
<b>Community level</b>		
Crime and violence	Both men and women cited crime and violence as a challenge for treatment adherence (-)	Some men spoke of being associated with gangs as an influence on treatment experience (-)
Stigma in community	Both men and women, particularly those co-infected, cited stigma as a challenge for adherence (-)	No differences between men and women
<b>Programmatic health service</b>		
<b><i>Facility related</i></b>		
Facility timings/waiting times	Both men and women cited facility timings/waiting times as a challenge (-)	No differences between men and women
Previous experience in facility	Both men and women on repeat TB treatment cited previous experience as having either a positive or negative influence on their current experience (+,-)	More women than men cited having experienced other services in the facility (as having a bearing, either positive or negative, on their perception of the facility (+,-))
Experiences with TB-related services	Both men and women cited positive and negative experiences with TB-related services as having a bearing on their treatment experience (+,-)	No differences between men and women
Stigma in facility	None	Men cited feeling uncomfortable seeking TB services in the facility (-)
<b><i>Treatment related</i></b>		
Side-effects	Both men and women raised challenges of side-effects as a challenge for adherence (-)	No differences between men and women

Pill-burden especially with TB-HIV co-infection	Both men and women raised the challenge of pill burden as having an influence on treatment adherence (-)	More men spoke of pill burden being a challenge particularly in the absence of family/friend support (-)
DOTS	Both men and women cited facility daily DOTS as a challenge for adherence (-). Some men and women indicated a preference for facility daily DOTS for enabling adherence over other treatment models (+)	No differences between men and women
<b>Provider related</b>		
Providers know their job	Both men and women reported positive and negative perceptions of providers' knowing their jobs (+,-)	No differences between men and women
Interpersonal communication	Both men and women reported positive and negative perceptions and experiences of providers in terms of verbal and non-verbal behaviour demonstrating respect, listening, empathy, confidentiality. (+,-)	No differences between men and women

Key: (+) indicates factor was experienced as positive and enabling treatment adherence; and (-) indicates factor was experienced as negative and challenging treatment adherence.

### What is the influence of providers' gender on patient treatment experience?

During interviews and FGDs, patients were asked directly about their experiences and perceptions of providers' gender and their own preferences regarding gender concordance (see Appendices 8 and 9). Their responses were then used to generate initial codes on gender concordance (i.e. 'provider gender does not matter', 'patient preference for female provider', 'patient preference for male provider'). Table 6.3 below presents for each facility, patients' preferences and explanations in their own words with regard to gender concordance.

Overall, across facilities, both men and women indicated no special preference for gender concordance on condition that providers were respectful (Table 6.3). At the same time, there were preferences by both men and women for female providers on account of them being perceived as caring and empathetic. In a few instances, men and women indicated a preference for providers with the same gender for gender-specific conditions. Black African men indicated a preference for male providers because they were uncomfortable with young, female providers (Facility 2) and Coloured men objected to male providers because of perceptions of homosexuality and masculinity (Facility 3). In a few instances, women noted feeling uncomfortable with male providers because they feared that there might be transgressions of acceptable behaviour (Facility 2).

**Table 6.3: Gender-related preferences for providers**

		Sample quotes		
		Preference for male providers because....	Preference for female providers because...	It does not matter if the provider is male or female because...
Facility 1	Male	-	I see the females here and say “listen here, I need a week’s tablets” and they will say “No, no problem”. There, by the Day Hospital I say to the other male “I need a week’s tablets” and he would say “why do you want a week’s tablets?”. Because female is understanding ... I mean man to man, talk is not right. But a woman to man, is right man. Man to man no I am not comfortable ... They [women] got also children man you see. You would do everything for your children right? So, who am I? I am also a child [Participant is laughing] [P9]	To me it won’t affect my behaviour according to a female or a male you see. You get a female doctor, you get a female nurse you know. For me it does not matter who helps me as long as I get my pills ...[P6]
	Female	-	Because I am female. I think they understand better ... I am female and feel comfortable talking to a female. Sometimes you have female problems that have nothing to do with TB. [P6]	I don’t worry if you are a man or a woman that want to help me. I just want to get help and I want to get done and I just want to go home. That was my motivation. [P4]
Facility 2	Male	You see, we as men, we are very scared of injections [laughs]. You see that I am old and you [female provider] are still young and now you [female provider] are going to see my dry bum [laughs]. I would like for you to be a male nurse, to get injected by a male. When you [female provider] as a child look you will see an old man’s bum, you are young and educated but I get so embarrassed by getting an injection from a child in this small bum but I pretend to be strong because I want	-	I have no problem to be consulted by a female person, or a male person because I am that kind of a person who take everyone as equal, you understand. Male or female you are on the same level especially on the level of education, you understand. If the person is a nurse, male nurse or female nurse, they are on the same level. CCW on the same level, so I treat them equally, you understand. I have no problem

		to get better. Some people just decide not to come at all [to the facility] if they are going to be injected by a child ... it would be better if they did it like they used to because we used to get injected here, in the shoulder, but now they go to the unusual places. [P6]		with that. [male participant in FGD]
	Female	I think it would be better if a female is helped by a male because we have respect for men and when it comes to females I just think this is a female just like me. [P3]	I would say it is better to work with a female since I am also a female, because men act strange as time, so it's better to work with a female when you a female; firstly it's because men look at a lot of things when they are working with a female, they start telling you that you have a big bum, big thighs and whatever, and then that could make you uncomfortable and you avoid that person and when they bring your pills they will not find you, but when working with another female that female will never judge you, she will come with respect and give you your medication. [P8]	It is the same because even if it's a man you will come and tell him your problem and even if it's a woman you would tell her what your problem is and they will just do their part. [P11]
	Male	-	It is actually better for a female because a male is maybe different. Maybe as time goes he becomes <i>skew</i> [gay in Afrikaans slang] or so. He can become or maybe he is gay. You never know. Now he starts become all feely and touchy. [P3]	A good service, no matter what they are male or female ...[P2]
	Female	-	A female nurse is alright, it is better yes. Because I am also a female and I also think the same ...[P1]	Actually no because there's a male and a female coming to check up on my tablets; and they, they are the same actually. They motivate you, they both motivate you. [P7]

## What are the building blocks of interpersonal and institutional trust?

As stated in Chapter 3 (conceptual framework), patient trust is operationalised in this study as ‘patient confidence that the health care provider and the health system which they represent, works for the best interests of the patient and has the technical and personal competencies to do so’ (Russell, 2005). Moreover, patient trust comprises two levels; interpersonal and institutional.

As noted in the methods section, participants were not directly asked about trust, rather it was investigated indirectly in interviews, FGDs and observations, exploring topics that would illuminate events and experiences under which patient trust could be judged and constructed. The theoretical literature (Chapter 2) and the resulting conceptual framework (Chapter 3) suggest that the building blocks or antecedents for trust (both interpersonal and institutional) are closely tied with factors affecting treatment access and treatment adherence, i.e. factors which enable treatment adherence are similar to those for building trust in providers and the overall health system (See Tables 2.2 and 2.3 in Chapter 2). Judgements over how to capture experiences and emerging issues relating to trust were made through a combination of inductive and deductive analysis (refer to data analysis on second cycle coding under data entry and analysis procedures in Chapter 4).

The conceptual framework (including the definition of patient trust and its dimensions (i.e. vulnerability, expectations) and levels of interpersonal trust (assessment of technical competency and interpersonal communication) and institutional trust (e.g. provider training, range of services offered, patient rights respected and upheld) provided the basis for the deductive analysis and the generation of patient trust-related codes (e.g. expectations of providers to provide confidentiality). These conceptual and theoretically derived codes were augmented by additional inductively derived patient trust-related codes (e.g. expectation of providers to work faster, providers responsive to patients’ needs regarding flexibility of treatment). Final judgements over trust (or distrust) were derived from operationalising the definition in terms of expectations being met (or unmet).

Table 6.4 provides a cross-case analysis summary of patients’ trust in providers and the broader institutions in the facility and their composite factors, based on investigator judgements derived from inductive and deductive analysis.

### ***Interpersonal trust***

Across all facilities, patient trust in providers was founded on provider’s technical competence, interpersonal communication and providers’ responsiveness to patient needs.

**Table 6.4: Building blocks of patients’ trust in providers and the institution**

		Facility 1	Facility 2	Facility 3
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	<b>Patients' trust in providers based on expectations and experiences of:</b>			
Codes	Providers are technically competent	✓	✓	✓
	Providers' interpersonal communication demonstrating respect, attentiveness, care, empathy, confidentiality, reliability	✓	✓	✓
	Providers responsive to patients' needs regarding flexibility of treatment	✓	✓	✓
	<b>Patients' trust in the institution based on expectations and experiences of:</b>			
Codes	Facility timings	-	✓	-
	Other services in the facility (e.g. reception staff)	✓	✓	-
	Previous experience with the facility	✓	✓	✓
	Experiences with TB-related services (e.g. social assistance, nutritional supplements)	✓	✓	-

Key: ✓ indicates participants' expectations of factors which are judged to have a bearing on trust in healthcare providers and the institution. – indicates that the factor was not identified as an expectation of patients in that facility.

Expectations were shaped over several months over the course of treatment through multiple interactions with a range of TB healthcare providers, both in the facility (i.e. doctors, nurses, counsellors) and in the community (DOTS supporters and CCWs). Expectations related to both the technical competency of providers and their behaviour and attitudes.

#### *Providers are technically competent*

As described earlier, it was important for patients that providers 'knew what they were doing', and demonstrated this through being able to guide patients through the treatment regime and being able to respond to their questions in ways that reassured them:

He [doctor] sat me down and he said to me, "How do you take your tablets?" So I said, "All at once!" And he said to me, "You got a water tablet, you got the cholesterol tablet, you got a high blood tablet, you got this, now you still got all the colon tablets, now you still have your TB tablets. I'm going to tell you how you take your tablets.". He said to me, "You break up your tablets, take your tablet, every one and a half hours, take two tablets. You take your high blood and you take your water tablet. Then you take uh, that tablet and that one together, and you, you will see." And ever since, not once did I have an anxiety attack again. [P4, female, Facility 1]

She [TB adherence counsellor] explained everything to me and even showed me a book and said "do you see how TB is, it does this and this to your lungs" ... thereafter I knew what it was. [P1, male, Facility 2]

However, often patients were vague in their description of what their expectations regarding technical competency:

I think they are giving their best so really there's if, if anything else from, from my, my side that I'm gonna add to that I'm actually gonna lie because they really on top of their game ... [P4, female, Facility 3]

In my experience, in everything that I asked them they answered me in a right way ... I was able to get all what I wanted to know from them. [P1, male, Facility 2]

Patients expressed an expectation of consistent messages as an important influence on their perception of the provider and the health services. When patients perceived that they were being given conflicting information, particularly in relation to the treatment regimen, it raised concerns about the technical competency of the providers and their position as ‘experts’:

I was supposed to change pills the months ... but I did not ... I asked whether there was a reason ... They [provider] said no they just wanted to be sure that I am fine, I asked if that was not an overdose, and they said no and I said oh ... I was starting to give up because a person is supposed to change pills on the second [month] and then again on the third [month] and finish up on the sixth month. [P1, male, Facility 2]

Demonstrations of technical competency was also an expectation of patients. One such example was that of a physical examination. In instances when providers did not conduct a physical examination, patients questioned the completeness of the consultation and expertise of the provider. In the following quote, the patient had TB of the skin and a lump on her thigh. During the consultancy with the doctor, she reported that he was reluctant to touch the lump and she was dissatisfied with the consultation:

I don’t know if he [doctor] is embarrassed but I am not. If he is embarrassed then I don’t know. And I told him, “Doctor you can feel it”, but he just stares at it, he don’t even feel it so that he can tell me. So I said, now if I come again then doctor can *mos* feel if this thing is getting bigger, but he don’t. He just talk to you, he is a verbal doctor. [P4, female, Facility 1]

#### *Providers’ interpersonal communication*

Across the three facilities, for providers based both in the facility and community, the interpersonal dimensions of trust were established through experiences of being nurtured and encouraged in multiple engagements with the providers:

I found there is care in this clinic ... When I arrive here I found the nurses are always happy and full of joy ... the staff is treating me very well ... it makes me feel to be encouraged. [P1, male, Facility 1]

They [providers] care for us, they look after us, like they guide us at all times ... they have love, they do everything in a good way, in a right way, no one comes out crying ... [P2, female, Facility 2]

Apart from [CCW] just coming to count the tablets, you really feel that sense of importance. She asks, “How are you doing? Are you coping? How are you feeling did you find a job already?” You know so there is a bit of interaction so you kind of feel important and you kind of look forward to seeing [name of CCW]. And the sisters I mean they are phenomenal they, they always have something nice to say to you, “Nice to see you again, [name of patient]”. You know, people get to know your name and you feel it’s like a small family. [P4, female, Facility 3]

Providers acknowledging and responding to patients’ specific needs impacted on both their treatment experience and in some instances ability to adhere to treatment. These specific needs



often extended beyond the immediate illness and included both socio-economic and psycho-social vulnerabilities:

Even when she [CCW] arrives and find friends present she will pretend to be just passing as a person that is selling things ... but I know why she is there ... It must be me who will say “no feel free woman let us go inside the house and talk if the problem is big”. Sometimes she will praise me ... this woman is just encouraging me ... she tells me of my beauty and I can see that I am ugly. [female, FGD, Facility 2]

For four months, the sisters here they have been very supportive. And even the lady that comes to count my tablets, came out to the rehab to count my tablets. They were very supportive in my recovery. [P10, male, Facility 3]

Establishing an emotional connection with the provider in some ways permitted patients to share their personal constraints and appeal for assistance in relation to their treatment. There was also a need amongst some patients that not only should they be listened to but also be included in decision-making:

They [providers] asked me if it is okay if somebody comes to check me, check um ... My medication ... Once a week and I told them yes there's no problem. I was asked before they didn't just put it in place. [P1, female, Facility 3]

They listen and it is like yes they listen when I talk. And we don't just talk about treatment; like maybe the ones who like music we talk about that. It's almost like it is not just about the treatment. It is also about friendliness. Well like I said they are understanding, they are supportive and if there is a problem they will immediately see to it that the problem is solved. I am working and there are times that I can't come by myself, and all I can do is to phone them and ask them and then my sister may come or maybe my sister don't have time; they are available and will come when she is ready. [P11, female, Facility 1]

Patients' expectations of providers having positive attitudes which communicated friendliness and approachability encouraged them to visit the facility, share their experiences and adhere to treatment. This also implicitly required time, space and privacy:

They [providers] would talk to me and I would talk to them. They would tell me story and I would tell them a story. They would laugh with me and I would laugh with them and **that made me to come back every time** [emphasis added]... They would always have their smile on their face when I come here. They were never show they are angry even when [I] am complaining about the hours and all that. [P8, female, Facility 1]

In contrast, expectations of being chastised by providers, particularly in the presence of other patients, challenged expectations of being guided and supported:

I don't want to lie, I did get impoliteness from one of the sisters and I thought that I am new at this thing, I just started taking my treatment so I need that guidance and care like when you just had a baby you are supposed to give him attention when he is still small, it is the same when you are old and have a particular illness, you want to get that attention and guidance, and I was treated impolitely by one of the sisters who asked me if I am here for

treatment and when did I arrive. And I told her I was here yesterday and she said no we can't find your folder and I felt so offended because all that was hurting me, because I did not know anything and she made me look like a fool in front of people. She could not even follow up and say no I am sorry I got the folder, she just left me there alone feeling offended and small and did not even come to say that she was sorry, it was her mistake. [P4, female, Facility 2]

Patients also expected providers to be reliable in their behaviour and communication. For example, in Facility 1, a patient decided to take her treatment at the facility although there was a DOTS supporter closer to her, since on several occasions the DOTS supporter was absent when she went to her to collect her treatment, and she preferred to take her treatment at the facility:

I did drink my pillies [tablets] there by Aunty [name of DOTS supporter], near to my house. Sometimes Aunty [name] is not there, then I get cross, 'cause I can't drink my pillies, then I got a quarrel with her and she said "You go to the clinic and go drink your pillies at (the) clinic" and I come get to the clinic and I drink my pillies at the clinic. I don't feel nice because I want to get healthy, ah, ek wil gesond raak nou, as ek nie my pillies mos nie drink nie dan kan ek mos nie gesond raak nie .( I want to get better now, if I do not drink my tablets, then I cannot get better). [P8, female, Facility 1]

The above suggests that when patients' expectations were not met, they exercised agency in taking a decision to return to the facility. It should also be noted that the DOTS supporters revealed that on occasion they delegated the responsibility of overseeing the treatment and signing the patient's green card to their family members. While this was not verified through follow-up with participants, this practice might have also influenced patient's perception of their reliability and their trustworthiness.

While the above speaks to what patients minimally expect in the patient-provider relationship, there was also an expectation that providers go 'the extra mile' and acknowledge the person, beyond the disease and the treatment, underlying the importance of mutual respect and recognition:

They [providers] don't go as far as asking you, "How you are doing, are you alright, how are things going at home", they don't ask you that. They just do their job you see. Sacrifice from their side that is really awesome to me really; especially if a nurse or a doctor someone like that goes out of their way for his patient. That is an extra mile for me ... I haven't seen that from them. If you [provider] can't show me that extra mile, you don't have a feeling for what you do, you [are] just doing it just because it's [a] job you see ... it is not just a job because these [patients] are people man! [P9, male, Facility 3]

Some doctors don't want me to tell them what is right and what is wrong ... because I am child and they are big man ... I am grown up man, so treat me with respect and I will treat you with respect. [P9, male, Facility 1]

### *Providers acknowledging and responding to patients' specific needs*

The opportunity costs of facility timings and waiting time for income and household responsibilities were described earlier. In line with this, flexibility of treatment in recognition of patient challenges was a dominant theme across all facilities for both male and female patients:

The decision for me to drink treatment from home was taken because I told them I am going to keep coming here to drink my treatment I will need to always have R12 every day. So, I was not going to manage that and they must arrange for me to drink from home. They made arrangements for me to drink it from home. [P1, male, Facility 1]

Most of the times when I cannot come to the clinic because I must at work she [CCW] tells me that my work does not have to separate me from my pills, because of the job I will not be taking my treatment, she tell me that these things go together and I must not separate them, if I chose to do them at the same time, so she is there when I say I cannot come fetch my pills she comes to collect it for me because she knows when I am supposed to be collecting my treatment, I just give her my things and she would come to the clinic and collect it for me and when I have to see a doctor I know I have to come personally. [P4, female, Facility 2]

In addition, a short waiting time was affirming for many patients:

It is a very good clinic and when I always come here they are very prompt people. When you come here you wait in the queue until you wait for your turn and they help you with your tablets and your medication and afterwards you can go home. [P7, male, Facility 1]

In contrast, the lack of recognition of competing demands on patient's time was problematic for patients:

Other patients were going before me and then I asked her "Sister! Why you always let me wait so long". She said "No, you got nothing to do at home". But that was a very wrong answer she gave because I had a lot of things to do. [P6, male, Facility 1]

I wish they can work according to a system, they must work fast so that a person does not sit here for long, because other people must still go to work and if they sit here for long they become late. I am a student and sometimes I must come to the clinic for my medication and I run out of time and be late ... sometimes I end up missing two classes because I still have to catch a train so I end up late really. [P7, male, Facility 2]

However, in some instances, poor communication styles where facility-based staff were judged as often being in a hurry and disrespectful in their interactions with patients, discouraged them from sharing and disclosing what was important for them:

You [patient] even become afraid to disclose other problems. This person [facility-based provider] comes in in a hurry ... I cannot tell him what I was supposed to tell because he is in a hurry. I do not know why he is in a hurry because she has arrived at work. [female, FGD, Facility 2]

### *Overall judgements of providers' trustworthiness*

In this study, trustworthiness like trust was not directly investigated. However, during FGDs and interviews, patients often articulated their expectations of providers in terms of ideal attributes:

The sister should come in the morning and greet her patients, must be approachable, and if you have declined in taking the pills there should be no need to shout at the patient, she must be polite with you and tell you that ma'am or sir if you are not taking your treatment this and that will happen to you, this and that is going to happen in your life and if you don't want to take your medication such and such are going to happen in your life, the mistake that you just made now, they must treat it as a mistake and not start by shouting tell them that if you make this mistake again this and that will happen ... (P4, female, Facility 2)

In the above quote, the participant articulated the ideal attributes of a provider with respect to interpersonal communication (i.e. empathy, care) and competency, which correspond closely with the building blocks of patient trust described in Table 6.4. These building blocks can also be understood and judged as the circumstances of under which a patient would consider a provider trustworthy, where 'trustworthy' is considered a personal attribute or virtue (Hardin, 2002; Sellman, 2007). Fotaki (2014, p. 1287) defines it as '... the ability, benevolence and integrity of a trustee' and the trustor's (i.e. patient) judgement over trustworthiness of the trustee (i.e. provider) is important for enabling trust.

In this study, second cycle coding, which included interpretative judgements regarding provider trustworthiness, was based on both deductive and inductive analysis. A review of the literature (Hardin, 2002; Sellman, 2007; Fotaki, 2014) identified theoretical codes (i.e. ability, benevolence, integrity, reliability), and these were considered against the inductive codes (technical competency, interpersonal communication and responsiveness of providers), comprising the key elements or building blocks of patient trust in providers (see Table 6.4).

As illustrated in the quote below, negative experiences of a lack of empathy, responsiveness regarding interpersonal communication and technical competencies suggested for the patient that the providers in the facility were untrustworthy:

I sit alongside a woman in her 50s, who is passing the time with a book. She wears glasses and is attired in track pants, T-shirt and crocs. Her clothes are a little threadbare but clean and neat. She is very articulate and reflective. She shares her story with me. Her husband died a few years earlier and she lives with her daughter who is almost 30 years old. Both she and her daughter have MDR TB and they are unsure of how they contracted it. She has had a loss of hearing in one ear. She describes herself as adherent but admits having skipped her treatment sometimes. While appreciative, she is critical of the service. She always carries a book because she is uncertain of the waiting time. She says the following. "Patients need answers ..." "Nobody can understand what it is like to be on TB medication ... its makes you sick ... you have irregular bowel movement". She supports her daughter who is working by collecting her treatment once a week. She goes onto say "... staff communication is poor ... the staff ask me what medication I need! Can they not look through the folder? They are lazy and

unprofessional. Patients are reminded constantly of their responsibility, not to spread infection and be adherent but when there are stock outs, whose responsibility is it? This is unfair!” She relates an incident when she had an appointment with the doctor and waited and finally asked the whereabouts of the doctor, only to be informed that the doctor would be in in the afternoon and then after waiting for some time for the doctor was later informed that the doctor had “taken time off from work”. [Facility observations, 21 January 2014, Facility 3]

### ***Institutional trust***

Institutional trust was based on assessments that facility timings were convenient, experiences with other services in the facility, previous experience with the facility, experiences with TB-related services, and the perception and experience that all patients were treated equally (i.e. no preferential treatment).

### ***Facility timing***

While long waiting time was in some instances attributed to provider shortages (Facility 1 and 3), notably in Facility 2, it was also attributed to unprofessional attitudes and behaviour on the part of providers:

They [providers] are gossiping and we are seated on the chairs ... Sometimes we spend like 30 minutes without being consulted and they are busy gossiping that side ... this thing is happening again and again, it hurt us that people are gossiping but patients are sitting on the chairs. Why are they not taking care of patients? They should take care of patients first and after they finish they can gossip about their own things and enjoy. [female, FGD, Facility 2]

All facilities opened between 7:30 and 8:00 to accommodate working patients on daily DOTS or collecting their treatment. In Facility 2, patients felt compelled to arrive and wait even earlier, despite fears over crime, to avoid having to queue. This contributed to them feeling increasingly vulnerable, particularly when they perceived that the health facility was not responding appropriately to this issue:

Standing outside the gate, it's a risk. There are children who are on tik [drug], these children will rob us. They [facility staff] do not open that gate for us to [go] inside. Imagine the one who is working inside will arrive and close the gate while we are outside. He will say “You cannot [enter] when the sister has not arrived.” What is he [provider] saying about our lives because there are children who are smoking tik and they rob people? I was going to ask [that] they [providers] must change the time of opening the gate because there are people who are on casual jobs and they wake up early to stand in the queue and when they did not come they will be labelled as defaulters. [female, FGD, Facility 2]

The patient judged the staff and the facility as uncaring and not acting in the patient's best interests.

### ***Experiences with other services in the facility***

The behaviour and attitudes of support staff, particularly reception and clerks, also had a bearing on participants' experience and their willingness to seek care in the facility. In instances when participants cited examples of being treated poorly by staff, they were discouraged from seeking

care. This was particularly a challenge in Facility 2, where interactions with staff at reception were raised as problematic:

It's your first time [in the clinic] and you don't understand, they [reception staff] will not tell you nicely, they will just shout at you, it happened to me. I was deeply hurt because the clerks are old people and when you have been hurt by an old person you lose respect but fortunately I can control my feelings. [P8, female, Facility 2]

My child was still small I had just been out of hospital and I brought him for his 6<sup>th</sup> week check-up. The card that I had from the hospital said [name of place] because before I gave birth I was staying in [place] and thereafter I moved back home because I was at my sister's house there. So I went to the window [reception] and gave my card, I was then called and the sister that was there I won't lie, she really disrespected me, because what she did was to tell me I could not be here because my card says I must be in [place]. When I tried explaining the situation to her she said she was not going to listen to that so I took my card and my baby and went to [place] without getting any help and that was the last time I came to [Facility 2], I then took my baby to [place] from thereon. When I got to [place], I told the nurse who was helping me and she phoned here at that very moment and then the superior [facility manager] who was here that day phoned me from work and asked me to come here and then apologized. I told myself that I will not come here again because the person who did that to me at that time did not come to apologize only the superior [facility manager] apologized. [P3, female, Facility 2]

As described above, for some patients, women with children in particular, their previous experiences had a bearing on their intention to seek care at the facility. In the second quote, although the facility manager had apologised, the patient did not return to the facility, until she got infected with TB. As will be explored later, experiences with other aspects of the facilities' services, influenced patients' judgements relating to institutional trust and influenced the nature of their engagement with the facility and the providers.

#### *Previous experience with the facility*

Patients' expectations and trust in the facility were also built around previous experience with TB and other services in the facility. In the first quote below, the patient was experiencing a second episode of TB and he had been previously treated at the facility and had a positive experience. In the second quote, the patient describes her experience at the facility when her child was ill. Her child was diabetic and had been ill at the facility on several occasions:

You see this clinic is far from where I stay, but I choose it because it is the only clinic that can help me. I was helped there by facility [name] [referring to a previous case of TB] but they were so stupid there, but this one is the main one, this clinic is a very good clinic. They helped me and they make sure I take my tablets. They repeat it over and over even if I am getting tired of their words at times but they keep on saying I must take my tablets all the time. They keep on motivating me ... [P3, male, Facility 1]

I had a very good experience, very good and heart sore experience at the clinic. If that bed here next door [referring to adjoining consulting room] could speak, then that bed would tell you that I almost lost my baby. She got ill at home and she had 3 seizures, so that when I got here [facility], she was going into a coma. The sisters and the nurses here ... they carried me through. They were good to me and made sure the ambulance came

quickly enough, so that she did not suffer. They really supported me and encouraged me, they spoke to her and even kept the conversation going while the ambulance was on its way. Every time she gets sick, I am here at the clinic, they help me immediately. Always, when we sit [at the facility] and she starts to nag, there is always a piece of bread for her or a little juice for her, they always have something for us. [Female participant, FGD, Facility 1]

In contrast, negative experiences meant that patients approached the facility and the providers with caution. In the following quote, the patient had a son who had died of TB. The patient believed that his son had died because he was given the ‘wrong treatment’, challenging the patient’s confidence in the facility and the providers:

My son died of TB yeah ... Yeah he died of TB a couple of years ... and he come here for treatment and the sister said “no nobody of you got TB ...”so he died of TB he’s the only one who died of TB. [P2, male, Facility 3]

As will be explored in a later section, the patient’s own treatment experience was complicated by him being diabetic and infected with TB, and he questioned the provider’s technical competence in managing his co-illnesses, with implications for trust in the provider.

Several patients had experienced more than one episode of TB. For one of them, whose previous episode had been managed in the same facility, a second episode of TB reflected a treatment failure from the first episode:

Jeez I wonder why the clinic didn’t keep me on the treatment in the first place, I probably would not have gotten it again. The pills were just for six months then I had to stop and I am not a person that drinks or who lives an up and down life. [P1, female, Facility 3]

In the above, the patient believed that recurrence of TB was due to error on the part of the providers. However, the recurrence could have occurred for several reasons including relapse,<sup>26</sup> or reinfection through a different strain, or a consequence of treatment failure arising from either drug resistance or non-adherence to therapy. Her lack of knowledge suggested a gap in health literacy.

#### *Experiences with TB-related services*

Patients’ needs in some instances extended to a range of services relating to broader social needs (e.g. nutritional supplements and social grants). Experiences around these services often had implications for the patient’s overall perception and experience of the facility. As illustrated in the following quote, negative experiences with other aspects of the facility challenged patient’s overall experience of the services. The patient was unemployed and poor and he believed that he met the

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<sup>26</sup> recurrence of tuberculosis (TB) can be due to a regrowth of the same strain of *Mycobacterium tuberculosis* that caused the previous TB episode (i.e. relapse)

criteria for the provision of nutritional supplements<sup>27</sup>. However, he was not being given the supplements and he questioned the honesty of the social worker and the extent to which information was being withheld from him, raising concerns over her trustworthiness:

The social worker could not give me a straight answer [regarding provision of food parcels] ... I sometimes see people who come here [for food parcels] and I realize that lady [social worker] said we cannot get food parcels here ... but I don't know how it works and I would say I did not get enough information. [P6, male, Facility 2]

In another instance, an older woman with her grand-child (with TB and on the nutritional supplementary programme) had a very challenging relationship with the reception clerk who managed the distribution of the NSP milk and porridge to the patients:

In the TB waiting room, a young woman sits holding a small baby. Next to them sits the granny who shares with me her experience of the facility. She says, "She [TB PN] is nice and friendly, but that man [TB clerk] is terrible!" She speaks about how her heart starts to beat quickly ("and I get all worked up") when coming here, because she knows she is going to be in for a fight, though, "I am a very soft person, and I cry very easily". She says the struggle is with getting the milk that the TB clerk is in charge of, that he will only provide milk if she comes with the child [the TB clerk's policy of "No milk, no baby"] and that though the dietician has organized for the milk to be sent to [place where they live], he refuses. She says the difficulty is that she must come by taxi, with a haversack, and the child on her hip, to pick up eight heavy cans of milk, and then she must lug it all home. "I don't know where I can go to complain about him" she says. She says that, "They make you feel so small, it is like a power thing." She also says that there are designated times for milk collection (after 3pm on a Thursday and a Friday) and that she has been made to wait for four hours, unnecessarily before, when she has come earlier. She is visibly upset talking about this. It is evident, however, that TB treatment is only one aspect of patient-staff relationships, for most patients use this clinic for other needs, or TB needs spill into other areas. [Facility observations, 8 October, 2012, Facility 1]

Patient experiences were therefore complicated by the various other areas of the health services in which these relationships play out. As suggested in the above quote, gender also influenced experiences within the facility, as well as judgements over the trustworthiness of the providers and the institution. In the next section, a more detailed analysis of gender underlying the experiences of men and women and the implications for interpersonal and institutional trust will be considered.

## **Do men and women construct interpersonal and institutional trust differently?**

Table 6.5 below provides a summary of expectations of men and women in relation to providers and the institutions, which form the basis for assessing provider and institution-related trust. Overall, both men and women had similar expectations of providers, regarding both interpersonal and technical competencies. However, there were differences in relation to broader institutional factors.

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<sup>27</sup> The provision of nutritional supplements (i.e. milk and porridge) is based on an assessment of the nutritional status of the patient and is provided only to patients who are socio-economically vulnerable.



For instance, women more often raised previous experiences with the facility and experiences with other services offered by the facility as an influence on their expectations and pre-existing trust. In contrast, men more often raised as a concern that their broader socio-economic needs (e.g. need for social grant) were being ignored. The ability of providers and the health system to respond to patient needs more holistically regarding socio-economic and psycho-social support needs has been identified as important for treatment adherence, but is clearly important for trust too. Moreover, socio-economic and psycho-social challenges are also gendered and health system responses need to be cognisant of this. This will be discussed in more detail in Chapter 8 (Discussion).

**Table 6.5: Comparison of male and female patients' constructs of trust in providers and institutions**

	Similarities between men and women	Differences between men and women
<b>Trust in providers</b>		
Technical competency	Expectations of cues for providers' technical competency and responded similarly when expectations were met (+) or not met (-)	-
Interpersonal communication	Respect, listening, empathy, confidentiality.	-
Responsiveness to patients' needs	Empathy, act on needs, particularly flexibility of treatment and waiting time	More men expected providers to accommodate their socio-economic challenges and work-treatment challenges.
<b>Trust in institution</b>		
Facility timings	Empathy from providers in relation to the risks from waiting outside a health facility	-
Other services in the facility	-	More women considered staff at reception to be polite and respectful
Previous experience with the facility	Both men and women spoke of previous TB episodes as having a bearing on their perceptions of trustworthiness of the facility and its staff	More women spoke of accessing the facility for other services, and their treatment experiences as having a bearing on their perceptions of trustworthiness
Experiences with TB-related services	-	More men raised the challenges of the facility not meeting their expectations of accommodating their challenges regarding poverty and role as the household-head

Key: - indicates that participants did not have an expectation in relation to that factor.

## **Outcomes of trust and distrust in providers and the institutions**

Judgements over trust outcomes in patient behaviour and attitudes were developed deductively from the literature (Chapter 2) and conceptual framework (Chapter 3) and inductively. The literature on the role and outcomes of trust (Chapter 2) indicates that when trust is present, it

encourages patients to seek care, enables co-operation and supports patients feeling more comfortable to share information, including that which is sensitive, and finally encourages them to adhere to treatment. Lack of trust is associated with failure to comply with the recommended treatment, unwillingness to attend follow-up appointments, poor continuity in maintaining long-term relationships with medical providers, and eventually poor patient outcomes. This (i.e. deductive analysis) provided the basis for the generation of codes relating to outcomes of trust and trust in providers (e.g. following the treatment plan) and institutions. Inductive codes were derived from patient responses in interviews to questions relating to, for example, how they would respond to side-effects.

Table 6.6. summarises the cross-case analysis relating to outcomes of trust and distrust in providers and the institution. A key message from the table below is that trust leads to positive attitudes and experiences where, despite being vulnerable for multiple reasons, participants felt and indicated a willingness to accommodate provider (provider makes a mistake) and institutional challenges (e.g. long waiting time). In contrast, when trust was challenged, patients often expressed feeling uncared for and a desire to seek care elsewhere.

**Table 6.6: Outcomes of patient trust in providers and institutions**

	Outcomes/indicators of trust	Outcomes/indicators of distrust
<b>Trust in provider</b>	<ul style="list-style-type: none"> <li>• Feels safe, cared for</li> <li>• Less watchful</li> <li>• Speaks positively of staff</li> <li>• Follows the treatment plan</li> <li>• Open/honest interactions with and disclosing information to providers</li> <li>• More willing to give providers a chance when mistakes are met</li> <li>• Following-up with providers when there are side-effects</li> </ul>	<ul style="list-style-type: none"> <li>• Feels insecure, uncared for, disempowered, watchful, vigilant</li> <li>• Speaks negatively of staff</li> <li>• May or may not follow the treatment plan</li> <li>• With-holds information</li> <li>• Seeks care from other providers</li> </ul>
<b>Trust in institution</b>	<ul style="list-style-type: none"> <li>• Speaks positively of the facility</li> <li>• Willing to continue care at facility even when there are negative experiences</li> <li>• Tolerates long waiting time</li> <li>• Recommends the facility</li> </ul>	<ul style="list-style-type: none"> <li>• Seeks care elsewhere</li> </ul>

In the following sections, outcomes of trust and distrust are described in more detail with supporting data.

### ***Outcomes of trust***

Patients' judgements of trust in providers were based on assessment of both their interpersonal and technical competencies. For patients who had a high regard and respect for the providers, built around critical and multiple incidents, based on both interpersonal and technical competencies, it enabled co-operation between patients and providers:

I do not like to sit still for so long [laughter], you must just sit if you are to come and drink your tablets. Then Aunty [name of DOTS supporter] scolds me, then I walk out, then she says to me "I am telling you [name], if you go home then I am going to send the dogs after you, you are not going to get better if you do not drink your treatment". So I said to her, "I cannot sit the whole day, I must go and wash a lot of washing." She said, "Man, the washing can wait, sit so that you can drink your tablets". My bowl, the tablets is already there, the glass is there with my name on, then I swallow it and she then says, thank you [name], now you may go home. [female, FGD, Facility 1]

The mask is not nice but okay you have to put it on. It is understandable because why, TB spreads ... But a person has to put it on because there are sisters that come and check-up and so on. I have to respect them so I put the mask on. Although I know that I am on treatment and I can't spread it but I do it for them, because they are the people that help you. When you come to a place, respect and discipline, if you don't have respect then no-one will have respect for you ... So that is a place that you respect and those are people that you should respect; because those are the people that look after you ... [P5, male, Facility 3]

Doctor continues with her explanation, "They do two tests on each cough, the first one takes two days, the other one takes six weeks. If I were you ...". And the patient says immediately, "No doctor, I'm going to wait! I want to be sure, no problem". [Facility observations, Facility 2]

In the first quote (Facility 1), the patient of the sick diabetic child (described earlier), who was regarded as a challenging patient by the TB staff, conceded that she was impatient, but was willing to co-operate with the staff. Her trust in the provider was based on both an interpersonal dimension and having her expectation met that her medication would be ready (institutional reliability). In the second quote, when patients believed that providers were caring and acting in their best interests, it reinforced the interpersonal dimensions of respect, and appeared to enable co-operation in relation to institutional norms (e.g. policy of masks). In the third observation, trust in the provider's technical competency enabled co-operation, when the doctor was suggesting a laboratory test for the patient where the results will only be known six weeks later.

An additional indicator of patients' trusting the providers' technical competency was their response to side-effects. Many of them described that when they experienced side-effects, they did not independently decide to discontinue the medication, but instead reported and were treated for the side-effects:

My face is swollen and when I complained to the sister here at 1 she said "No it's because you just started [treatment]". They said "No, continue taking pills it will become right." While I was continuing, I developed pimples on

my face. The sister said they will too go away. Those are side effects. I said to her “No I do not like them. Worse something on the face, it would be better if they come from a hidden place.” I ask to see the doctor. The doctor gave me something to use, it took a week for them pimples on my face to go away. [female, FGD, Facility 2].

I would come here and tell them [providers] that my tablets are making me feel dizzy and they are treating me bad ... No I would not stop them ... I will tell the nurse that hey these tablets are treating me in this way and that way. [P1, male, Facility 1].

The interpersonal experience of providers as friendly and open also allowed patients to feel safe and be willing to reveal sensitive information:

... sometimes you just see this nurse is open, you can see the face is cheerful, oh ok I can reveal anything that I want ... there are different types of nurses, this one is scary, you just don't have to ask a lot of things, but some other one, you could see on the face before you can even get inside the room, you say yah, this one yah at least maybe I can talk to her ... here the nurses were so friendly. [P19, female, foreign national, Facility 1]

Patients who believed that providers acted in their best interests also appeared more willing not only to commend and praise the efforts of the providers, but also to acknowledge the challenges that providers faced in the course of their work, and connect with them on an emotional level beyond their therapeutic relationship:

You get those people [patients] that haven't sat for five minutes, then they complain that they want to be helped, that is wrong. The sisters try their best to help you. [P8, male, Facility 3]

I just think these people are doing their work properly. I don't have to complain about them because they also need bread like something to put on the table. So it is not viable to complain about other people because also they also have to live. They are also all children of God. They also have to settle their things you see. I don't want to complain about these persons. [P7, male, Facility 1]

This also led them to recommending the facility:

That is why I say these people are caring, they are loving and they are very, very helpful. That is why I will recommend anybody who got TB or want to come to TB treatment they must come to Facility [name]. [P10, female, Facility 1]

In addition, the patient felt that the services had improved tremendously, so much so that she reproached another patient who was complaining:

Things has change turned around in the last year... Dramatically and drastically in service in general ... But this person [another patient] just happened to say “boy this clinic is slow and look at the service and I'm waiting too long ...” And I actually turned around and I said [to the other patient] “Look, listen, madam. I'm at this clinic every second day and can I tell you how much service have improved in all areas at this clinic so I'm very proud to say the service you receiving today is their best; and [on] any God-given day, when all the staff are here you we actually get excellent service...”. [P4, female, Facility 3]

### ***Outcomes of distrust***

In contrast, when providers did not meet patients' expectations (i.e. were perceived as less trustworthy), based on a judgement of either a lack of interpersonal or technical competencies, or both, they considered alternate options. For example, a patient in Facility 1 on community DOTS felt that his green card was not being consistently signed each time he took his treatment, and that the community DOTS supporter provider was unprofessional, since she was financially abusing the relationship and disrespectful in her conduct. He decided to take his treatment at the facility instead:

I take them [treatment] here [facility] and don't take them by other people's houses [community DOTS] ... If I take tablets there by other people's houses, they don't make you sign, but here [facility] they make you sign that you were here and drinking your tablets you know. There is another lady [community DOTS] here in [name of place]. She [community DOTS] wants something, I must pay her or I must give something man. I just say I am going to buy a packet of biscuits and drink for her because she wants something ... She shouts at me and she gets cross ... [P3, coloured, male, Facility 1]

The above suggests that although the patient distrusted the community DOTS supporter, he trusted the providers in the facility, based on his judgement of their technical competency.

In contrast, negative experiences meant that patients approached the facility and the providers with caution. In the following quote, the patient had a son who had died of TB. The patient believed that his son had died because he was given the 'wrong treatment'. Moreover, the patient's own treatment experience was complicated by him being diabetic and infected with TB, and he questioned the provider's technical competence in managing his co-illnesses:

My son died of TB yeah ... Yeah he died of TB a couple of years ... and he come here for treatment. So I don't want to give her [doctor] the full information, you are a doctor, you [she] must tell me. I said to her "Okay I got TB and I got diabetic sugar". Diabetic, she look into a book and she couldn't find any conclusion what is wrong with me. So her advice was "It's your TB that makes you sick" so I said "No" and she only gave me 8 pain tablets. I went to the doctor especially for this especially for this and she don't even wanna to touch me. Hey, this woman, this doctor tell me it's my, my TB and I don't believe her [doctor]. If she can tell me it's my sugar I can believe her a little bit ... [P2, male, Facility 3]

This is also an example of an extreme case of mistrust of the providers, where the patient choses to withhold information in order to assess the technical competencies of the provider. In addition, the absence of a physical examination is a further indication of the provider's lack of technical competence.

## **Concluding Remarks**

In summary, treatment experiences and ultimately treatment adherence by patients with TB were influenced by a range of influences operating at the personal, community and health service level. While many patients expressed a deep desire and motivation to complete their treatment, challenges, often operating simultaneously at the different levels, conspired to reduce their capacity to adhere to treatment. Patient vulnerability emerged as a critical influence over both treatment adherence and trust. Vulnerability was not limited to the illness, but was a complex outcome of intersecting factors at all levels (personal, community and health service level), across which gender was in many instances an underlying influence. The ability of providers and the broader institution of health care to recognise and respond to patient needs beyond the illness, to socio-economic and psycho-social support, was critical for building trust and enabling adherence. While in many instances, trust enabled adherence, it was not a sufficient condition for adherence. Finally, the outcomes and benefits of trust in providers and the institution extend beyond adherence to include cooperation. The role of healthcare providers, particularly the contribution of CCW as trustworthy 'access points' (Giddens, 1991) for patients, is critical for ensuring continuity of care. These issues will be discussed in more detail in Chapter 8 (Discussion) and their implications for policy and programme direction will be considered in Chapter 9 (Conclusion).

*I am instrument of God and have been chosen to do this work. This helps me make sense of my life. (TB assistant, female, Facility 1).*

## **Chapter 7: Provider experiences and their influences on relationships of trust in patients**

In this section, provider experiences - shaped by their expectations and experiences of patients, the workplace and their individual level characteristics and motivations - and ways in which it influences their relationships with patients will be examined. More specifically, the discussion will be framed and explored in relation to the following questions:

- How do TB providers behave towards patients with the potential to influence adherence?
- In what ways are providers' behaviours and attitudes influenced by their:
  - Assessments of patients' trustworthiness and what are the outcomes?
  - Individual-level characteristics and motivations to work as healthcare providers?
  - Assessments of workplace trust and what are the outcomes?

To ensure anonymity, all research participants referred to in this chapter are described by their role (e.g. doctor, TB assistant etc.), sex (i.e. male, female) and facility location (i.e. Facility 1, Facility 2, Facility 3).

### **How do TB providers behave towards patients with the potential to influence adherence?**

In the previous chapter, providers' attitudes and behaviour was shown to be an important influence on patients' overall experience, treatment access and adherence, and assessments of trust. These experiences and perceptions represented those of patients and were captured mainly through interviews and FGDs. In this section, observed provider behaviour and attitudes - categorised broadly as positive and negative - with the potential to influence adherence are described (See Table 7.1. below for a summary of these themes and corresponding categories and codes from the cross-case analysis). In the observational notes, all names have been anonymised.

These behaviours and attitudes are presented from the perspective of the 'outsider' (i.e. research team), captured through observations. The purpose of presenting it from the 'outsider' perspective is not to present an 'objective' view, but rather to add an additional perspective which can be compared and contrasted with the experiences of patients described in the previous chapter. The

observational data were those captured by the research team and there was triangulation by data source (i.e. across researcher observation notes and with interviews).

Behaviours were categorised as positive or negative depending on their potential to enable or challenge adherence respectively (Table 7.1.). Examples of what comprised positive and negative behaviours were first derived deductively drawing on relevant theoretical literature, followed by inductive analysis of the observational data. The theoretical literature (Johansson *et al.*, 1999; Holtz *et al.*, 2006; Noyes *et al.*, 2007) identified provider interpersonal communication both verbal and non-verbal as important for patient experience and treatment adherence. Both positive (e.g. greeting and addressing patients by name) and negative behaviour (e.g. scolding patients) on the part of providers were identified. Deductive analysis provided an initial list of codes which were applied to the transcripts. Inductive analysis of the transcripts generated a wider and more context-rich set of codes. The inductive codes included, for example, 'admitting patients for inpatient care when requested' and 'flexibility of DOT model'. This was followed by second cycle coding, where the codes were reorganised and regrouped into high-level conceptual categories (e.g. supportive encouragement, disrespectful communication practices and behaviours).

In Table 7.1, the theme of positive behaviour and attitudes was grouped under the categories of respectful and relationship-building communication, supportive encouragement, and accommodating patients' constraints and concerns in treatment decisions. Negative behaviour and attitudes was captured under the categories of disrespectful communication practices and behaviours and unsupportive behaviour. Table 7.1 also indicates whether the behaviours and attitudes were observed in facility- or community-based staff or both.

Across all facilities, respectful and relationship-building communication was observed. Patients were frequently observed being greeted by name, banter and humorous exchanges were often observed between patients and providers, particularly in Facilities 1 and 3<sup>28</sup>. Supportive encouragement through expressing concern for treatment-related and psycho-social experiences of illness was observed across all facilities by both facility and community-based staff. However, sharing personal experiences and physical touch was observed more frequently in Facility 1. Providers' willingness to accommodate patients' constraints was observed equally across all facilities.

With respect to negative behaviour and attitudes, labelling of non-adherent patients, scolding patients, not informing patients when they were taking a break, and lack of concern for treatment-related and psycho-social experiences of illness was observed across all facilities. Facilities 2 and 3

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<sup>28</sup> Although respectful communication was observed in Facility 2, it was not as frequent observed as in the other two facilities.



stood out for sexually-inappropriate exchanges with patients and discrimination against foreign nationals, respectively. Facility 3 was also the only facility where privacy for patients receiving injections was not observed.

**Table 7.1: Observed positive and negative provider behaviours and attitudes towards patients across facilities**

	Facility 1	Facility 2	Facility 3
<b>Positive behaviours and attitudes</b>			
<i>Respectful and relationship-building communication (verbal and non-verbal)</i>			
Greeting and addressing patients by name (verbal) <sup>1,2</sup>	√√	√√	√√
Eye contact during engagement (non-verbal) <sup>1,2</sup>	√	√	√
Humorous exchanges with patients (verbal and non-verbal) <sup>1,2</sup>	√√	√	√√
<i>Supportive encouragement (verbal and non-verbal)</i>			
Sharing personal experiences (verbal) <sup>1,2</sup>	√	√	-
Physical touch (e.g. hugging, touching) (non-verbal) <sup>1,2</sup>	√	-	-
Concern for treatment-related, psycho-social experiences of illness <sup>1,2</sup>	√	√	√
<i>Accommodating patients' constraints and concerns in treatment decisions</i>			
Providing information on disease, treatment regime, side-effects, follow-up in facility and community <sup>1,2</sup>	√	√	√
Asking questions about patients' personal and social circumstances <sup>1,2</sup>	√	√	√
Admitting patients for inpatient care when requested <sup>1</sup>	√	√	√
Flexibility of DOT model <sup>1,2</sup>	√	√	√
<b>Negative behaviours and attitudes</b>			
<i>Disrespectful communication practices and behaviours</i>			
Not informing patients when they are taking a break <sup>1</sup>	√	√	√
Not greeting and addressing patients by name <sup>1</sup>	-	√	√
Scolding/shaming older patients in presence of others <sup>1</sup>	-	√	-
Scolding/shaming/threatening patients who have defaulted and/or not observed policies of the facility <sup>1</sup>	√	√	√
Making patients wait <sup>1</sup>	√	√	√
Labelling of non-adherent patients <sup>1,2</sup>	√	√	√
Providers entering consulting room during consultation without knocking and interrupting consultation <sup>1</sup>	√	√	√
Lack of privacy for patients receiving injections <sup>1</sup>	-	-	√
Discrimination against foreign nationals <sup>1</sup>	-	-	√

<b>Sexually-inappropriate exchanges with patients<sup>1</sup></b>	-	✓	-
<i>Unsupportive behaviour</i>			
<b>Lack of concern for treatment-related and psycho-social experiences of illness<sup>1</sup></b>	✓	✓	✓

1: (1) indicates **Behaviour/attitudes associated with facility-based staff (bolded)**; and (2) behaviour/attitudes associated with associated with community-based staff. (✓) indicates the observation of the factor in the facility, and multiple ticks (✓✓) indicating that the observation was more frequently observed. (-) indicates that the behaviour/attitude was not observed. Source: facility and community observations.

### ***Positive provider-patient interactions***

Across all three facilities, providers, both in the facility and in the community, were generally observed as being respectful, supportive and responsive to patient's needs. Cues for respect included courtesy, addressing patients by name and light-hearted exchanges with particularly patients who were known. Facility 3 was striking for the warm relationship between the TB enrolled nurse and drug-resistant TB patients. In this facility, drug-resistant patients, who were almost all men, had started an informal support group, which included them taking their treatment together in the facility. It was often observed that while they waited, they would chat conformably among themselves, discussing their treatment, side-effects and how they were coping:

At 9h00, the EN calls in a group [four male and a female] of Coloured patients who are on MDR treatment. There is an exchange of warm greetings between the EN and particularly the male patients. The EN asks them how they are doing and the men are clearly very relaxed and comfortable in this space, teasing and joking with each other and the EN. The EN nurse requests that the men leave the room since she wants to administer the injection to the woman first. They agree and one of the men teases the EN "it is a lady's world because they always get the first preference in everything" provoking laughter from the others. One of the others responds "I am used to seeing women's behinds because I've got 5 sisters". They leave the room but remain in the waiting room and once the woman has received her injection, they return and tease each other constantly as they take their injections in turn. The female patient has defaulted her treatment and the EN encourages her to persevere. There is also lots of encouragement and support from the male patients and their share their own stories and experiences of the MDR treatment and how they support each other and the help they receive from the TB staff. [Facility observations, 17 January 2014 Facility 3,]

Across all facilities, interactions which included screening, counselling and adherence and periodic follow-up with providers both in the facility (e.g. adherence counsellors, nurses, doctors) and community (CCWs) were in general positive, characterised by providers' behaviours and attitudes which communicated care, empathy, attentiveness and supportive encouragement:

Patient: "Doctor, I have a new job." [Doctor is elated: "I like the fact that you have a job, I'm so happy! Since you are working, maybe your girl-friend can fetch your meds? But you still need to come in. If you are not feeling well, you must also come back to the clinic. How much do you weigh? "]

Patient: 46.5 [kgs] [Doctor is clearly happy with his weight: “43, 45, 46! Going up and up, good news!” She then pastes his X-Rays on the X-ray screen and concludes: “No TB, continue with the treatment. How is your girl-friend and her treatment?”]

Patient: “She is eating her treatment” [Doctor advises “You guys must help each other. Tell me about your work”.]

Patient: I’m working on a construction site”. [Doctor: You must remember to carry lunch with you. I am very happy with your weight. [Facility observations, 15 April 2013, Facility 2]

In addition, providers, especially those working in the community, through the sharing of their own life experiences of either having TB or other challenges (e.g. poverty, unemployment), offered themselves as examples of ‘success’. Besides encouraging patients to adhere to treatment, this also appeared to build an emotional connectedness between patients and providers:

In the informal settlement, we meet a young woman whom is non-adherent. She is so thin that she is wearing two jerseys even though it is very hot. She is living in a very small shack. [Name], the TB assistant is following-up on her for a sputum since she has failed to return to the facility. She manages to cough and give some sputum to Fiona. The woman tells [name] that she is struggling to survive. [Name] responds that she understands how difficult life is; she has “been there”. She describes her own life experiences. There was a stage in her life when she was unable to pay her rent, she had no money, and there was no electricity. She was at the “bottom” and “God saved her.” [Name] encourages her to look out and to have a vision for herself and tells her that she is beautiful and young and pleads that this should not be her life. She talks about her vision – [Name] envisions herself being thin - and the woman smiles. However, she also says to her that it is best if she stops the other drugs before taking the TB meds. [Community observations, 24 October 2012, Facility 1,]

Observations also revealed ways in which facility-based providers empathised with and attempted to accommodate patients’ challenges. In the following extract of observations in Facility 2, a wheel-chair bound patient was unable to collect his medication and this responsibility fell on his wife. The providers believed that the wife was not coping under the multiple demands of her husband’s illness, his caregiving and their children. The provider convinced the wife that a hospice would better serve his needs and relieve her burden:

Enrolled Nurse (EN) (female) says to the wife of the patient, “There are well trained nurses in hospice and they know what they should do. So you should not worry because he will be taken care. They will feed him, wash him and at least for two months you can have time to focus on your children and your house”. The wife agreed and the EN called the hospice and arranged a bed for him. [Facility observations, 11 April 2013, Facility 2]

### ***Negative provider-patient interactions***

Negative behaviours and attitudes mainly included instances of providers disrespecting and being unsupportive towards patients. Disrespectful behaviour included failing to greet and acknowledge patients, lack of information, unresponsiveness in relation to patient questions and finally, a consistent pattern across all facilities where providers failed to inform patients that they were

leaving for a break. In many instances, this incited objection and in some instances, anger on the part of patients. Unsupportive behaviour included instances when providers ignored and/or expressing a lack of concern for treatment-related and psycho-social concerns of patients.

Negative behaviours also included instances of lack of professional competencies. In the following extract, the patient requested screening for TB and was offered at the same time, an HIV test. However, he was not counselled as required under the HCT guidelines (National Department of Health no date). In addition, the test was not offered in a private room, but in the DOTS room. There was no evidence of informed consent, confidentiality and counselling, and the overall impression was of a lack of engagement and interest in the patient on the part of the providers:

A young male patient, mask, black cap comes in and sits down closest to the door. He does not greet anyone and neither is he acknowledged by Nurse [name], the male EN. Nurse [name] walks over to him and I do not hear any conversation. The door remains open. Shortly after, the patient signs a form, which I am later told is an informed consent form. Nurse [name] does a finger pick test. When was the patient been counselled? I did not hear it happening? Nurse [name] gives him a cotton wool which the man presses to his finger and he returns to his seat and completes the form, interrupting only to ask the patient questions. During this time, it appears that [name] has completed capturing the patient's history and is now asking him for a sputum sample. A label containing the patient's name and details is stuck on the jar. Nurse [name] motions towards the sputum booth, which is outside the DOTS room. He demonstrates that once the patient has coughed sputum into the jar, he needs to secure it securely. During this exchange, the patient is silent and walks towards the sputum room and starts to cough noisily. The coughing clearly irritates Nurse [name], who scolds the patient and I hear him closely the door behind him. He returns with a jar shortly after, hands it over to Nurse [name] and leaves without greeting anyone. As with the previous patient, nobody acknowledges his departure. [Facility observations, 4 April 2013, Facility 2]

In addition, across all three facilities, there were two groups of patients who provoked negative responses from providers. The first included those who were perceived as rude and demanding:

The TB waiting room is full and patients appear to be impatient, pacing, the corridor, some even complaining loudly about the waiting time. The PN is in the DOTS room, counselling a patient and although she does not respond to the complaints, she seems flustered and overwhelmed. She complains to the DOTS supporter that she had not had a tea-break since morning, who instructs "You're going to tea now, you're going before you do those [TB] suspects". [Facility observations, 16 October 2012, Facility 1]

The CCW supervisor enters the DOTS room and her annoyance is clear. She lets off steam, reporting to the Enrolled Nurse that she told a patient that "This is "not a fish and chips shop where you can just say you want fried hake and chips, and they dish it out for you! At a clinic you have to wait, everything isn't just ready for you. "You must wait!" [Facility observations, 3 April 2013, Facility 2]

The second group were non-adherent patients. These patients were labelled as "defaulters", "chronic defaulters", "missing link", "drifter", "stoute klong" [naughty boy] by providers, often

requiring intense follow-up with them and their social networks. If the providers perceived a lack of responsibility underlying poor treatment adherence, the repercussions were severe:

Sr [name], the TB PN and Auntie [name] the DOTS supporter, proceed to give [patient name] a severe scolding. Auntie [name] asks him, "Where have you been for the past 2 days?" He responds, eyes downcast, "At home". She insists that she knows he wasn't at home, because his mother has called to say he hasn't been there, and she is worried. Working in tandem, Sr [name]s and Auntie [name] chastise him, "Wil jy nie lewe nie?" [Do you not want to live?] They tell him that he will kill his whole family, by infecting them, that they will tell his friends, who won't want to spend time with him when they find out he has a strong form of TB they can catch. [There is reference to his doing drugs with his friends]. Auntie [name] tells him that they have no obligation to treat him when he arrives sick from not having taken his medicine; that they will leave him, and then he will die. [Facility observations, 18 October 2012, Facility 1]

Although not widespread and specific to Facility 2, another extreme form of negative interaction between providers and patients included male providers transgressing patient-provider boundaries through engaging in sexually inappropriate exchanges:

Male Nurse: Are you using condom? [Patient: No, I am not in a relationship]

Male Nurse: Why? [Patient: (she looks away and then at the nurse, smiling): I don't want to be in a relationship.]

Male Nurse: What do you say there in your work place when others are talking about relationships? [Patient: What am I going to talk about? (laughing)]

Male Nurse: You are a grown up woman.... [Patient: They ask me when do I have sex and I tell them that I am not concerned about sex]

Male Nurse: You are getting old. [Patient: (Laughing, she looks directly at the nurse and leaves and returns). "You forgot to write a date here on my card".]

Male Nurse: It is because I was charming you. [Facility observations, 19 April 2013, Facility 2]

Again, although not widespread, but striking because of its recurrence in Facility 3, was the negative interactions and lack of respectful engagements with foreign nationals, particularly Somali patients. In the following observation, a Somalian male, who seemed to be unable to communicate effectively in English, was observed several times attempting unsuccessfully to get the attention of the providers in the TB room:

A Somali male is sitting in the TB waiting room amongst the MDR patients. The EN is counseling a male patient in the TB room and the Somali male patient enters the room. The EN tells him in English that he must wait since she is still busy with the other patient. The Somali male does not leave and he does not appear to understand. She repeats what she has said and gestures for him to leave. He nods his head and returns to the waiting room. After the male patient left, the EN calls in a Somali family (male, female, baby). The woman is unable to communicate in English and the man, communicates on her behalf in response to questions from the EN. During the consultation, the TB assistant who was present, but until that moment silent, asked the man brusquely "So why

are you rushing us and the child is not even here?” The man seems offended and ignores her. He turns to the EN, pointing to the TB assistant; he asks “What is her problem?” At this moment, the other Somali male re-enters the room and the TB assistant impatiently waves him out “Just go wait, we busy with other patients”. He continues waiting and the EN once again gestures for him to wait outside. He appears discouraged and leaves the room. The family leaves shortly and he is called in. The EN offers him a seat, asks him his name and why he is at the facility. He is only able to provide his name and over the next few minutes she struggles to get his background information. The TB assistant then rushes out to find the Somalian couple, hoping that they, or at least the male, will be able to facilitate the conversation. She is not able to locate them. The EN is able to extract from him that he lives with his brother. She then writes a note and asks him to hand it over to his brother. During the consultation, she appeared to be shouting at him. After he left, the EN comments that “These people are very demanding, they do not want to wait.” [Facility observations, 28 January 2014, Facility 3]

As will be explored later, observations of social distancing and negative stereotyping of Somali patients appeared to be rooted in providers’ views of them as foreigners and their associated rights to services in South Africa.

## **Explanations for providers’ behaviours and attitudes towards patients**

In this section, influences on provider behaviour will be considered in relation to 1) providers’ expectations and experiences of patient as trustworthy; 2) providers’ individual influences; and 3) providers’ expectations and experiences of the workplace as trustworthy.

### ***The trustworthy patient***

Drawn from interviews with providers, Table 7.2 provides a summary of the categories associated with each of the dimensions linked to judgements of trustworthiness and untrustworthiness.

Providers’ perceptions of patients’ trustworthiness (and untrustworthiness) were based on assessments along the dimensions of emotional competency, technical competency and integrity.

Since providers were not directly asked about trust and trustworthy behaviour in relation to patients, these judgements were made in the process of interpretative analysis. Rogers (2002) identifies patient competency (e.g. follow provider instructions, complete their treatment and to know when to seek care) and integrity (e.g. speaking the truth, sincerity) as important for providers to be able to judge their trustworthiness, which informed the deductive analysis. The inductive analysis identified emotional competency (i.e. patient is demotivated, chronic defaulter, lack of concern for public health risk of TB) as an additional dimension of competency.

Across all facilities, patient emotional competency, assessed by provider judgements over treatment commitment and motivation was important. Technical competency, assessed by provider judgement over patient being knowledgeable about TB, treatment adherence, ability to follow treatment guidelines correctly and reliability in treatment collection, was more frequently identified by providers in Facility 2. Importantly, Facility 2 was also the site with a high TB-HIV co-infection

burden and a fully-integrated TB-HIV programme. In this facility, co-infected patients received intensive counselling and community support to enable adherence to a complex treatment regime. Integrity and recognition, judged by providers' views on honesty, respect and appreciation was frequently mentioned across all facilities.

**Table 7.2: Providers' assessments of patients' trustworthiness and untrustworthiness (source: Provider interviews)**

Dimensions of trustworthiness and untrustworthiness	Codes	Facility 1	Facility 2	Facility 3
<b>Patients' trustworthiness</b>				
<b>Emotional competency</b>	Committed to their health/Motivated to treatment	√√√	√√√	√√√
<b>Technical competency</b>	Knowledgeable about disease, adherence treatment regimen	√	√√√	√√
	Follows treatment guidelines correctly	√	√√√	√√
	Reliable in treatment collection	√√√	√	√
<b>Integrity and recognition</b>	Honest in communications	√√√	√√√	√√√
	Respectful in communication	√√√	√√√	√√√
	Appreciative of the provider	√√√	√√√	√√√
<b>Patients' untrustworthiness</b>				
<b>Emotional incompetency</b>	Uncommitted to their health/demotivated	√√√	√√√	√√√
	Repeat episode of TB and 'chronic defaulter'	√√√	√√√	√√√
	Lack of concern for public health risk of TB	√	√	√
<b>Technical in-competency</b>	Poor knowledge of TB, treatment regimen, unable to correctly follow treatment guidelines	√√	√√√	√√
	Unreliable in treatment collection	√√√	√	√
<b>Lacks integrity and recognition</b>	Rude towards healthcare providers	√√√	√√√	√√√
	Transgresses boundaries which compromises providers' safety	√	√√	√√
	Dishonest in communications/behaviour	√√√	√√√	√√√
	Patient abuses alcohol and/or drugs	√√√	√√√	√√√
	Opportunistic behaviour	√√	√√	√√

√ indicate presence of factors identified by providers in the facility, with more Vs indicating mention by several providers

In this section below, affirming attributes of patients, with illustrative quotes, which build providers' assessments of their trustworthiness, will be discussed.

### *Emotional competency*

A dominant provider narrative across all facilities was the expectation of the central role of patients in acknowledging, taking responsibility for their illness and treatment, and ultimately being compliant and treatment adherent:

I think you respond better to patients that take responsibility for their own health, and through that I mean their adherence number 1 ... [if] a patient is non-compliant; there's a million causes why a patient would be non-compliant ... Violence in the community especially in the surrounding area like shootings, like people won't come out of their houses if there is a shooting going out in the street ... They won't come to the clinic to get their medication. If it is something that is actually quite valid then you try and accommodate the patient; and you work around the patient... [Doctor, female, Facility 3]

If providers perceived that the reasons underlying patient's poor treatment adherence were driven by factors outside of the patient's influence (e.g. lack of family support, poverty, complexity of treatment regime) and not an absence of emotional competency, they were more willing to find ways of supporting them and as illustrated below, sometimes even materially:

[Name TB assistant] used to give him [patient] taxi fare to come [and say to him] "look here [name], you must be here again tomorrow nê, so here's taxi fare to come up tomorrow" and he would use it and he would come ... [TB PN, female, Facility 1]

### *Technical competency*

Technical competency was judged on the basis of patients being knowledgeable about the disease, treatment and adherent to the treatment regimen:

If they are going to the chemist they must say that they are taking the TB treatment, and I also encourage them to know their pills by name and not say the orange pill or whatever, they must know their pills. [TB PN, female, Facility 2]

The emphasis placed on patients 'knowing their pills' was also linked to the TB-HIV burden being experienced in Facility 2 (and to some extent Facility 3), where providers identified adherence being a challenge for patients who were dual-infected. They argued that these patients were either in denial or overwhelmed by the complex treatment regime and pill burden associated with TB and HIV. As illustrated in the following quote, often a multiplicity of factors (i.e. TB-HIV co-infection, absence of social support, treatment literacy) interacted to hamper treatment adherence:

... he already defaulted treatment ... he said yes he wants treatment again, so we started the whole process of counselling and everything, gave him his treatment after the time and then the next two weeks he comes for a check-up and a pill count and the things are crazy ... and I get the pill box and we start...we start explaining the pill box again and we put some stickers to try to make it easier and next week he is still confused, doesn't know



what is going on and then I started making him a weekly patient and I only gave him his box with his tablets and he came back and it was better ... then I spoke to him and said "Look what do you wanna do?". He said, "I live alone and sometimes I have got a problem with remembering". He said no I want to come to you every week, and he comes to me every week gets his box filled and he comes to me every week, he doesn't, rain or shine he is here with his box. [Doctor, female, Facility 2]

The above quote also illustrates that providers were willing to accommodate patients whom they perceived as motivated and responsible, but the complexity of their treatment regime challenged their technical competency.

### ***Integrity***

Patient integrity was assessed around expectations of patients being respectful and honest in their communications and appreciative of the efforts of the providers. As illustrated in the following, providers appreciated and valued patient honesty, even in instances when it comprised adherence:

They [patients] say "Sister I'm gonna be like honest with you now tomorrow it's Christmas, oh it's New Year then I'm gonna take a drink". Then I say "Yes take a drink but don't overdo it because you know it's not good for the health". "No Sister but just I just want to let you know ..." [TB assistant, female, Facility 3]

### ***Is patient trustworthiness gendered?***

As described in the previous section, judgements regarding the trustworthiness of patients was derived through a process of interpretive analysis involving inductive and deductive coding. Similarly, judgements over whether providers judged men and women to differ in being trustworthy was arrived at through interpretative analysis. In interviews (see Appendix 11), providers were asked directly about male and female patients (e.g. "What issues affect patients' ability to complete their treatment and do male and female patients experience these issues differently?" "From your experience, do male and female patients behave differently towards you as woman and do you have a different relationship with them?"), informing the inductive analysis and the resulting codes (e.g. Gendered perception of patients). The deductive analysis was informed by the conceptual framework where dimensions of trustworthiness included emotional and technical competency and integrity and recognition.

The general and dominant perception held by providers was that men were less adherent to treatment than women (see Table 7.3 below). There were various explanations advanced for this. It was often argued that men ignored their illness, and when they eventually did seek care, their poor communication practices (i.e. unwilling to disclose and engage in open and honest communication with the providers or disrespectful practices) challenged the ability of providers to manage their treatment. Men were thus experienced as less trustworthy. Women on the other hand were perceived as more willing to seek care and commit to the treatment plan, since they were often

motivated by concerns over the livelihoods of their children. Interestingly, in Facility 3, men who had been previously in prison were considered the exception in treatment adherence. The ways in which this sub-group of patients were perceived as trustworthy had implications for the ways in which providers engaged with them and facilitated treatment access.

While this was the dominant perception, there was also the perception that there were few differences in adherence between men and women, and when they did exist, they were a consequence of individual-level challenges and competing demands on patients' time. In addition, culturally defined gender roles, particularly those relating to the household roles, were also seen as a social barrier to treatment, particularly for women (see quotes for Facility 2 in table below). Interestingly, providers seldom recognised that men might also have household and child-care responsibilities which could influence their treatment adherence.

**Table 7.3: Providers' perception of gender-related differences in terms of treatment adherence**

Gender-related differences	Sample quotes		
	Facility 1	Facility 2	Facility 3
<b>Men are less treatment adherent and less trustworthy</b>	You must have hair on your teeth, for the men ... Because they want to tell you, "I don't want to drink my tablets today" or "I don't want this and I don't want that" .... they are full of crap ... they give you a hard time ... [DOTS supporters, female]	People who are posing challenges for us are males It's mainly the men ... mostly men died [from TB], there were few ladies but mostly guys ... ignoring about using condoms, ignoring about health in general, they [men] said "No its flu not TB". [CCW, male]	Most of the time it's men who are non-compliant but again in this area we have a lot of drug abuse ... [Doctor, female]  The male is more challenging but I get there ... males, they're very closed up ... I think men are stronger in that way because they I don't know I guess it's a guy thing. They don't really talk, "I'm strong, I'm not supposed to cry, I'm not supposed to talk about my problems" ... But most of my females, you would actually see them cry about the fact that they do not have food, they're stronger in going to a neighbour, and ask for a piece of bread ... where a guy wouldn't do that.

			[adherence counsellor, female]
<b>Men are more treatment adherent and trustworthy</b>	-	-	There are patients coming from Pollsmoor [prison], they, you know they wear these tattoos and have slang ... they are also very disciplined because they come from a prison whereby they are trained to be disciplined ... I've never had a defaulter from prison. (PN, female)
<b>Women are less adherent and trustworthy</b>	-	... TB treatment for a woman is a disadvantage ... A woman must wake up early in the morning to boil water for this man to bathe, cook for him and prepare for the children to go to school and then take treatment. Washing is also waiting for her. If she stays in the informal settlements she has to carry water to and fro ... [TB adherence counsellor, female]	Females are generally more jumpy, they will jump at you. "I have to get my children from school" ... and then also you would find that females always have the kids with them, so now they have to worry about the children not eating and they're not eating and you know all of those stresses [PN, female]
<b>Women are more adherent and trustworthy</b>	Women take their treatment better. It is better to work with them because you are also a woman [DOTS supporters, female]	Females are better ... Females are afraid of dying because when you advise her to take pills because she will die and leave her children she is shocked and take the pills. [CCW, female]	The women, even the young women they are more compliant to the medication [CCW, male]
<b>No differences between men and women in adherence and trustworthiness</b>	There are other factors that actually determine adherence ... The gender you know, working men and working women versus, unemployed men and unemployed women, those are very, very different. I	I also want to say they [men and women] are similar [CCW, female]	-

	think you may well see more similar behaviours in unemployed individuals rather than in genders ... [Doctor, male]		
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### ***Outcomes of trust in patients***

The cross-case analysis outcomes of provider trust (and less trust) in patients are summarised in Table 7.4 below. Inductive and deductive analysis informed the judgements over provider behaviour and attitudes as outcomes of trust. Rogers (2002) indicated that when providers trust patients, they monitor them less and there is the potential to improve quality of the patient-provider relationship (Chapter 2). Lack of trust is associated with increased monitoring and providers enforcing boundaries in the relationship (van der Walt and Swartz, 2002). In interviews, providers were asked to describe their ideal and less-than-ideal patients and their behaviour towards them, and this contributed to identifying inductively trust-outcome related codes (e.g. provider feels valued and appreciated). This process of inductive coding of interviews was triangulated with observational data, which generated additional codes (e.g. scolding patients). Table 7.4 indicates that patients were viewed as being either trustworthy (i.e. cooperative, adherent and taking responsibility for their illness) or untrustworthy (uncooperative, non-adherent and irresponsible) with no obvious middle position.

**Table 7.4: Outcomes of trust in patients**

	<b>Outcomes of trust</b>	<b>Outcomes of less trust</b>
Providers behaviours and attitudes	<ul style="list-style-type: none"> <li>• Less monitoring</li> <li>• Respects patients</li> <li>• Willingness to listen to patients' challenges and accommodate them</li> <li>• Builds a relationship with patient beyond the immediate illness needs</li> <li>• Feels valued and appreciated</li> </ul>	<ul style="list-style-type: none"> <li>• Increased monitoring</li> <li>• Judgmental of non-compliant patients</li> <li>• Feels betrayed by patient</li> <li>• Scolding patients</li> <li>• Enforcing personal and professional boundaries</li> </ul>

Providers were more empathic and willing to accommodate patients they considered trustworthy. There was less monitoring (e.g. permitted to take their treatment under supervision in the community) and a willingness to find ways of accommodating them. In the second quote, the provider decided to allow patients with MDR TB to take their treatment together:

... most of the times when I cannot come to the clinic because I must at work she [CCW] tells me that my work does not have to separate me from my pills ... when I say I cannot come fetch my pills, she comes to [facility] collect it for me. [P8, female, Facility 2]

The reason why I'm doing that that they must come in together because they can relate to each other's feelings how they feel and whatever ... [EN, female, Facility 3]

Providers recollected with pride and a sense of accomplishment particularly challenging patients whom they were successful in encouraging to adhere to treatment:

At first you might not get along with them but when they are about to finish the treatment they thank you and say they are well because of you ... When they leave saying I have helped them I feel very proud of myself. My dream was to become a teacher to help the community so even here I am some sort of a teacher but doing a different thing so I become very proud of myself [EN, male, facility 2]

As noted in the above excerpt, for providers who had been unable to fulfil their initial career aspirations, recognition and appreciation on the part of patients also served to confirm that their current roles could also be fulfilling. Further, recognition and appreciation also connected with providers own professional goals which were driven by their intrinsic motivation (e.g. playing an uplifting role in their community).

As described earlier, providers often attempted to support patients, particularly in adherence challenges (e.g. lack of food, psycho-social support, transport to the facility). However, when these efforts were not appreciated, it was demotivating for providers:

There's one patient that I go out of my way, he was a defaulter, twice ... so I said to him, "Seeing that you on heroin, I am going to book you in." [Patient replies] "Yes sister, please book me in because I am staying on the street because I got no food." I organise everything ... all the family was here and they were so thankful that the patient is organised in hospital ... that patient abscond from the hospital, he was only 2 days there ... All my hard work. [TB PN, female, Facility 1]

Non-adherent patients were expected to return to the facility and take their treatment under supervision, were given additional adherence counselling, and in some instances, were referred back to the doctor. Further, when providers perceived patients having transcended professional and personal boundaries in their relationship (i.e. disrespect), they felt justified in responding in a manner that might be considered otherwise unprofessional. For example, a patient of the facility had reportedly stopped his treatment on account of finding employment and the providers felt that they needed to 'threaten him' by speaking to his new employer and informing them that 'he is going to affect their people'. This is further illustrated by the following facility observations. In the first observation, an adolescent male who was non-adherent received a severe admonishment from the

TB providers. In the second quote, an elderly man with TB was new to the facility and his green clinic card was incomplete:

The TB PN and DOTS supporter proceed to give [name of patient] a royal dressing down. The DOTS supporter asks him where he was for the past two days. He responds, eyes downcast, "At home". She insists that she knows he wasn't at home, because his mother has called to say he hasn't been there, and she is worried. Working in tandem, TB PN and DOTS supporter chastise him, "Wil jy nie lewe nie?" [Do you not want to live?] They tell him that he will kill his whole family, by infecting them, that they will tell his friends, who won't want to spend time with him when they find out he has a strong form of TB they can catch. [There is reference to his doing drugs with his friends]. DOTS supporter tells him that they have no obligation to treat him when he arrives sick from not having taken his medicine; that they will leave him, and then he will die. [Facility observations, 18 October 2012, Facility 1]

The DOTS room, is full, occupied by staff and patients and the EN is speaking with an old man in a wheel-chair. A younger man stands behind him. She says that the patient hasn't signed the card every day to indicate that he has taken his pills. I ask, "They didn't explain to him properly?" She asserts that they [providers] almost certainly did, but that patients always blame the facility when they have done something wrong. The younger man laughs awkwardly. The EN continues that no matter how old someone is, "We're not going to keep quiet" about them not filling in their card. She says that if the card is not signed he is going to have to come to the clinic every day to take his tablets "old as he is". [Facility observations, 3 April 2013, Facility 2].

Assessments of the trustworthiness of patients had implications for how providers negotiated, relaxed and in some instances enforced the professional boundaries in the relationship with patients. In instances when patients had transgressed professional and personal boundaries, providers reacted strongly. In the following example, a male patient was sexually inappropriate towards the PN:

We were struggling with this guy, he was just very, very inappropriate ... I figured out a way to manage him, you know very strict, assertive and no eye contact with this patient. There was close contact, but I managed him the whole time. [PN, female]

While facility-based staff were able to assert their authority, and power over non-adherent patients, and delineate personal and professional boundaries, CCWs were not able to draw on the same resources and were often less assertive and cautious in similar situations. CCWs trod carefully negotiating access to and building relationships with different clients. As noted earlier, they felt vulnerable because of their lack of professional status, coming from the same communities in which patients lived. Even when patients were challenging and at times disrespectful, they tried to accommodate their needs, particularly when they believed that there could be a threat to their personal safety.

For providers who lived in the community that the facility was located in, it meant that the boundaries between their professional lives were less distinct, and often contributed to the

community turning to them for health-related issues, even emergencies. While some providers (e.g. TB assistant and CCWs) did not discourage this and in some instances welcomed it, others found it intrusive and unwelcome:

It used to happen a lot, even 3 o'clock, 2 o'clock in the morning, they come and knock at my doors; and shout at the gate. Then I said "No, I've got a personal life ... I've got a family I'm not trauma ... and when I'm off duty I'm off from work ... There's a police station, go there I'm very sorry ..." My son said one day [to a neighbour needing health-related assistance] "Can't you see my mommy is on holiday? My mommy don't work for you ..." [TB supporter, female, Facility 3]

Sometimes they [patients] even make use of you in their personal life you know. There's no boundaries, there's no time limit ... Yes so my door is always, always open ... When you at the beach, they will find you. They ask you "Hey Sister sorry to disturb hey". You get it at the shopping mall, all over because you're a community worker...There's no boundaries ... [CCW, female, Facility 3]

### **Summary**

The above discussion provides compelling evidence of how providers provided supportive encouragement to patients, through expressing concern for treatment-related and other experiences of illness. More specifically, they recognised and often empathised with the challenges operating at the personal, community and health service/programme level that patients faced which affected their ability to adhere to treatment. However, there were also instances when they demonstrated a lack of concern for treatment-related and psycho-social experiences. Overall, patients needed to demonstrate that they were trustworthy, judged by a combination of self-motivation (emotional competency), commitment to the treatment plan (technical competency), integrity and recognition of providers. In some instances, gender norms and stereotypes on the part of providers influenced their views that men and women interacted with them differently, responded differently to treatment and commitment to the treatment plan.

### **Provider individual level influences**

In this section, personal attributes of the provider and the workplace and ways in which those affect provider motivation and experience will be considered.

Table 7.5 provides a cross-case analysis of factors motivating (and deterring) different healthcare providers. Motivation was not directly investigated in the study, but was interpreted through provider responses to specific questions in the interview (e.g. "How did you come to be working as a \_ [profession]?" ; "Have you ever thought of leaving this post and working in another clinic?" Appendix 11). The inductive analysis produced motivation-related codes (e.g. own experience of TB). A deductive analysis, drawing on a typology of intrinsic and extrinsic factors motivating and

detering health workers described by Greenspan *et al.* (2013), was then conducted, contributing to the final list of codes and categories in Table 7.5.

**Table 7.5: Motivation for choosing to work as a healthcare provider**

Categories	Codes	Facility 1			Facility 2			Facility 3		
		Doctor	Nurse	NGO staff	Doctor	Nurse	NGO staff	Doctors	Nurses	NGO staff
Intrinsic and non-financial motivations										
Personal TB experience	Own experience of TB (+)	-	-	√√	-	-	√√	-	-	√√
	Family/friend experience of TB (+)	-	-	√√	-	-	√√	-	-	√√
God’s work	Fulfilment of religious obligation (+)	-	-	√	-	-	-	-	-	√
Wanting to make a difference in the lives of others	Potential for uplifting community (+)	√	√	√√√	√	√	√√√	√	√	√√√
	Fulfilment from healing/curing sick individuals (+)	√	√	√	√	√	√	√	√	√
Opportunities for personal and professional growth	Opportunities for professional growth (+)	-	√	√	-	-	√	-	-	√
	Opportunities for personal growth (+)	-	√	√√	√	-	√√	-	-	√√
Role in the community	Recognition /respect in the community (+)	-	-	√√	-	-	√√	-	-	√√
Extrinsic financial motivations										
Financial need	Only income earner (-)	-	-	√√	-	√√	√√√	-	√√	√√
	Parental pressure (-)	-	√√	-	-	-	-	-	-	-
Available employment opportunities	Limited options available (-, +)	-	√√	√√√	-	√√	√√√	-	√√	√√√
	Stepping stone to permanent/ better paying position (+)	-	√	√√	-	-	√√√	-	-	√√

Table key: (+) Motivator; (-) Deterrent (Greenspan *et al.*, 2013); √ signifies that participants mentioned factor as a motivator or deterrent; more vs indicating mention by several healthcare providers

Provider motivation for choosing to be a healthcare worker was broadly captured under the themes of intrinsic and non-financial motivations, and extrinsic financial motivations (Table 7.5). Across all facilities, the desire to make a difference in the lives of others was most frequently identified as an intrinsic motivator by providers, irrespective of professional category.

The picture changes with respect to financial motivators (i.e. financial need and available employment opportunities). Financial need was not a motivator for doctors in contrast to nurses and NGO staff. Many NGO staff and nurses (with the exception of Facility 1) mentioned being the only



income earner and limited opportunities for alternate employment as a financial motivation. Therefore, while doctors were primarily in the profession, and in this instance the public sector, because of intrinsic non-financial drivers, a combination of intrinsic non-financial drivers and extrinsic financial drivers motivated the decisions of nurses and NGO staff.

### ***Intrinsic drivers***

Almost all providers (both facility and community-based) spoke of ‘wanting to make a difference’, ‘carrying out God’s work’ and ultimately carrying a passion for caring, which motivated them to work in the health sector and specifically with people infected with TB:

I am instrument of God and have been chosen to do this work. This helps me make sense of my life. (TB assistant, female, Facility 1).

I used to read about this thing HIV and TB and all this stuff and it was like a stepping stone to become a CCW; because now I can like actually see the people and they are living every day and how are they with their treatment ... I help them taking their treatment, motivating them; what is TB, give them speeches, talk to them ... **the work is meaningful** [emphasis added] [CCW, female, Facility 3]

Sometimes you get frustrated but I come to work to do my work. I never complain, I never panic because it’s not about myself; and I’m not worried about money or whatever. It is the passion that you will have for your patient or the community and is by helping the patient it’s not about myself and that is how I survive. [EN, female, Facility 3]

While both facility- and community-based providers spoke of being driven by a need to uplift communities, the latter (i.e. CCWs, DOTS supporters) were driven by an additional consideration. They lived in the same communities that they worked in and viewed the community as an extension of themselves, often referring to them as ‘our people’, whom they felt compelled to help even when their work was challenging:

Young people are smoking. It’s scary. You are scared going to them ... We are having tough time. Because we are working for our people, we cannot desert them. [CCW, female, Facility 2]

Additionally, a personal experience of TB (either self, family member or friend) also implied a personal transformation, which sensitised and motivated them to engage in caring work:

I’d worked as a cleaner in the clinics but felt “no man I want to do more for the patients, because I’ve seen the condition. I’ve heard their voices, I’ve heard them screaming out for help, there’s not enough staff and that’s why I become a TB DOT...I also had two brothers who also die from TB”. [TB assistant, female, Facility 3].

Moreover, working in TB and specifically with the most socially-disadvantaged provided an opportunity for learning and personal growth:

We are lucky and we need to give thanks for a lot of things that we have, we are privileged ... one of my patients who lives on the *stoep* of somebody else's house and it just makes me feel a little bit more grateful ... (doctor, female, Facility 2)

I love my work, I love being a DOT supporter ... I think I've got a passion for people ... I don't like to hurt people ... So I have got a few people [DOTS patients] at my house and you know we educate them every day about coming, taking medication and things like that ... it's a nice journey ... [community DOTS supporter, female, Facility 1]

A few mentioned that they entered the health caring profession because of their parents having been healthcare workers:

Both my parents, (laugh) were nurses. My mother was a matron at [name], and my father was at [name] and that is like followed you ... and my interest also to want to help people and just to care for people. [PN, female, Facility 1]

Generally, almost all providers found their work rewarding:

... I feel a greater sense of reward when I see that patient at six months and be cured and walk away very happy ... [Doctor, male Facility 1]

... all of a sudden somebody will come and say "Hi sister" ... I became a familiar face to them [patients] and also they people would come with other problems ... and I would see how I could assist them ... I loved working there, because it was at the most enjoyable I found was working with the very poor people ... [TB assistant, female, Facility 1]

### **Financial drivers**

Almost all the providers, with the exception of the doctors, spoke of life-long hardships including growing up in poverty, which challenged their ability to pursue their ambitions of tertiary education and professional jobs:

"I'm one of seven children; some of us got education ... My parents were factory workers ... I never wanted to be a nurse, that was my mother's dream, "my child I want you to be a nurse". I wanted to be a social worker; then decided I wanted to be a teacher after passing matric but my daddy said "financially I'm not ready for you because you didn't tell me that you want to go for a teacher". [EN, female, Facility 3].

Many of the providers (nurses and NGO staff; male and female) were single parents with dependent children and/or grand-children. They, particularly lower cadre staff (i.e. DOTS supporter, CCWs, counsellors, enrolled nurses), spoke of being motivated by a need for financial security. This often discouraged them from considering alternate work even when they were dissatisfied in their current position:

I am just saying at my age it won't be easy for me to go back to school because I have children and what would they eat or how would they go to school if I go back myself? I have to earn a living because if I stop working now I would be killing them. [Enrolled nurse, male, Facility 2].

“My man werk’ie, ek werk’ie, ek depend on daai stukkie geld.” [My husband does not work, I don’t work, I am dependent on that little bit of money]. [Community observations, DOTS supporter, 9 October 2012, Facility 1].

In the second quote above, the DOTS supporter had a larger workload than the others in order to increase her earnings. She spoke candidly of her poverty and being the only breadwinner in a household where her husband and adult children were unemployed. Unlike the others, she was financially dependent on the income from the stipend and she often felt that she did not have much of a choice, but to make every effort to follow-up those patients:

Aunty [name of community DOTS supporters] points to her shoes saying “They are worn out from walking and chasing down defaulters even to the shebeens”. (Community observations, DOTS supporter, 9 October 2012, Facility 1]

Overall, while providers acknowledged the importance of financial need driving their initial decision to take the job, many of them eventually grew to value the work they did, and saw it as opportunity for making a difference and personal growth:

I think at first I was just thinking, you know I needed money, just to carry me along but you know when I received this little money it didn’t bother me, it really didn’t bother me because the client came first ... you have to be compassionate towards them, you know so if I didn’t work with TB people and maybe I would have looked at people differently the way they are dressed ... they don’t smell nice ... so that also it teaches you not to look down on other people [facility DOTS supporter, female, Facility 1]

## **Healthcare providers’ experiences of the workplace**

Across all facilities, expectations and experiences of the workplace were an important influence on providers’ overall experience, with implications for their engagement with patients. These expectations and experiences are captured under the themes of interpersonal and institutional trust (Table 7.6 below). Interpersonal trust was constructed around relationships with co-workers, supervisors and managers. Institutional trust was built on expectations and experiences of working conditions, organizational culture of the health facility, human resource practices, and the broader TB health policy and service delivery context. In Table 7.6, provider expectations are indicated by “√”, and positive and negative experiences by “+” and “-”.

As will be observed in the discussion below, providers’ experiences differed, depending on their professional status and position in the organisational hierarchy; and whether they were employed by either City Health or an NGO. NGO staff situated lower in the organisational hierarchy (i.e. CCWs, DOTS supporters, TB adherence counsellors, assistants) had very different views and experiences of management compared to other NGO staff ranked higher in the organisational hierarchy (i.e. professional nurses, doctors).

**Table 7.6: Building blocks of interpersonal and institutional trust in the workplace for healthcare providers**

Categories	Codes	Facility 1			Facility 2			Facility 3		
		Doctor	Nurses	NGO staff	Doctors	Nurses	NGO staff	Doctors	Nurses	NGO staff
Interpersonal trust built on expectations (√) and experiences of (+, -)										
Relationships with co-workers	Team work		√ (+)	√ (+)	√ (+)	√ (+)	√ (+)		√ (+)	√ (+)
	Psycho-social support		√ (+)	√ (++)			√ (++)			√ (++)
	Professional competency of co-workers		√ (-)	√ (-)	√ (+, -)				√ (+, -)	
Relationships with supervisors, managers	Appreciation/ recognition		√ (- -)	√ (- -)	(+)	√ (+)	√ (- -)	(+)	√ (+)	√ (+ -)
	Respect		√ (- -)	√ (- -)						
	Caring		√ (- -)	√ (- -)			√ (- -)		(+)	√ (- -)
Institutional trust built on expectations (√) and experiences of (+, -)										
Working conditions and	Workload		√ (- -)	√ (- -)	(-)	√ (+ -)	√ (+ -)		√ (+ -)	√ (- -)
	Working hours			√ (- -)			√ (- -)			√ (- -)
	Resources to enable work			√ (- -)			√ (- -)	√ (-)		√ (- -)
	Safety and security			√ (- -)		√ (-)	√ (- -)	√ (-)	√ (-)	√ (- -)
Human resource practices	Salaries			√ (- -)		√ (-)	√ (- -)			√ (- -)
	Education, training opportunities		√ (-)	√ (-)					√ (+)	√ (+)
	Mentoring and counselling		√ (- -)	√ (- -)			√ (- -)	√ (- -)	√ (+)	√ (-)
TB policy /service delivery context	Target setting		√ (-)	√ (-)		√ (+-)	√ (- -)		√ (-)	√ (- -)
	Administrative load		√ (- -)						√ (-+)	

	Organisation inclusiveness						√ (- -)			√ (- -)
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Expectations indicated by √; positive experiences indicated by +; negative experiences indicated by –

## ***Interpersonal trust***

### ***Relationships with co-workers***

Across the three facilities, relationships between providers (i.e. facility- or community-based) could be generally described as supportive and collegial, which in turn were influenced by cadre (i.e. doctors, nurses, NGO staff) and location of work (i.e. facility- or community-based). Teamwork and supportive relationships were observed and reported by providers who interacted frequently with each other (i.e. CCWs and DOTS supporters in the community, and NGO staff and nurses in the facility). For example, the DOTS supporters demonstrated team work through assisting each other by collecting the treatment of the other's patients from the facility and if they lived close to each other, they would also temporarily oversee the treatment of patients of the other. Across all facilities, they reported working in pairs when required to follow-up challenging and non-adherent patients, particularly in locations they found unsafe. In some instances, providers also followed-up on their co-worker's clients:

We support one another because we had a brother here called [name] [CCW]. Hard worker! That brother was working. He did not care whether the person [client] is not his. If he came and find discussion on the client that was defaulting, staying at this place and at this number, he will take his backpack and go there. [CCW, female, Facility 2]

Within facilities, providers, particularly the nurses and NGO staff (TB assistants, counsellors), also described examples of teamwork and supportive relationships:

I think that we [facility DOTS supporter, TB assistant and PN] worked fairly well together. We helped one another and we conferred you know, if we weren't sure about something ... as I was totally new to TB, so a lot of our decisions that we made, we made together. [PN, female, Facility 1]

We are three [TB/HIV] counsellors and we help each other ... sometimes it is difficult to work with men but since I am surrounded by males I sometimes refer them to [name of male TB adherence counsellor] and tell him that they are difficult ... we motivate each other as counsellors, when the mentor is not available I talk to my colleague and I would be less stressed when I get home, a bit light. [TB/HIV adherence counsellor, female, Facility 2]

The second quote also highlights ways in which relationships between co-workers extended to mentorship and psycho-social support. As will be discussed later, this was critical and valued, particularly in the absence of formal mentorship and counselling from the employing organisations.

Expectations and perceptions of professional competencies were also important. Professional competencies were noted with respect to technical (i.e. providers had the necessary competencies)

and interpersonal competencies (respectful and caring in their engagement with patients). Both positive and negative experiences were noted. In the following quotes, poor experiences of professional competencies are highlighted in the first two quotes (poor technical competencies in quote 1 and disrespectful provider attitudes and behaviour in quote 3):

She [PN] was very “slap”. [I] can’t help saying that ... she [PN] was too slow and that used to stress me out. Because for me the client must not sit too long in the clinic ... you can’t let someone sit for a whole hour in the clinic and that really worked on me ... She’s a very thorough person, she is a very good person, but just with TB, you can’t be that slow ... we [TB assistant and the DOTS supporter] had to support her [PN], we had to comfort her, we had to tell her “Don’t worry, things are going to come right.” It did somehow affect us. [Facility DOTS supporter, female, Facility 1]

She [TB assistant] said the previous sister [PN] said to her, she can do that. And I said to her, you cannot do, the patient’s observations and urinary things if you not a nurse, you’re a TB assistant. But she said, but I was doing it all the time. And I said to her, nowhere, nowhere, I see people writing in red in patient’s folders. You only write in red when the patient died, then you write that in red. That is what we learn at Groote Schuur ... the TB assistant was working out of her scope, she was doing more the sister’s [PN’s] work. [TB replacement PN, female, Facility 1]

Both men [nurses] can ah can be silly and I will tell them they are being silly because they sometimes say things that’s silly and inappropriate, even comments about doing pap smears and examining if there is an STI, I mean we are professional people and I mean like it’s completely out of line ... Just to learn how to speak to people [patients] a little bit better and not to parent, not to ridicule ... it’s a partnership more than a parent child relationship and I think that is a bit of a challenge ... when you are shouting at somebody and they [patient] say “You know what, I don’t want to go back there because I am tired of somebody shouting at me in front of others”. [Doctor, female, Facility 2]

The [TB] enrolled nurse, she’s brilliant and she treats everybody with the same respect. [Professional nurse, female, Facility 3]

### *Relationships with supervisors and managers*

Relationships with supervisors and managers were important, particularly for providers lower in the hierarchy (i.e. nurses, NGO staff). Expectations and experiences of appreciation, respect, care and supportive supervision were raised by them across all three facilities. While nurses recalled instances of management recognising and valuing their contributions, this was rarely the experience of NGO staff:

The [sub]district manager came into the TB room and she commended me. It was an afternoon, I was just busy cleaning up the desk and dusting ... She came in and she commended me on the cleanliness of the room and the job well done ... I was just so shocked ... She was just very, very sweet and you know [she] commended me on the work that I’m doing and the admin that they are receiving. [PN, female Facility 3]

Yesterday our [facility] manager had a meeting with us, just the TB staff that’s working in the TB room. And she will always say “thank you for what you do” and we appreciate that. Like this morning, we were so surprised this

morning all of us. She [facility manager] said we don't have to go to our room, we have to stand there in the staff room. So we thought "What is going to happen now? What we do wrong?" and she said to us "No you didn't do anything wrong" and she give us all a rose with our name on "thank you for the hard work ...so that was a nice surprise this morning. [EN, female, Facility 3]

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They [NGO] do not recognize what we do, not unless you did not reach your stats, they don't recognize you. Clinic wise, City of Cape Town as much as we do a lot, when it comes to awards, they only take [recognise] the sisters [nurses], "Thank you sisters here is an award". I have been here for five to six years but I never heard that a counsellor has won for the best employer of the year. [TB adherence counsellor, male, Facility 2].

We get cure rate, 98, 98 percent and she [supervisor] not even like pitching up to the meeting to say thank you ladies. We are also human, we also work, sometimes we also need to talk about our situation, almost ten months, she's never here ... It is upsetting us because she [supervisor] is never here. [FGD, DOTS supporters, Facility 1]

The second quote besides highlighting the demotivation arising from the lack of recognition, also draws attention to the challenge that dual management structures (i.e. being managed by the NGO and being located in City Health facilities) had on NGO staff. This was further challenged by them having limited access to and engagement with supervisors and management from their employing organisation. This was compounded by the perception that neither the NGO nor City Health acted in their best interests or recognised the challenges under which they worked. The importance of visible and active supervision was recognised by a programme manager of one the NGOs:

Many of my colleagues will tell you that I'm a hands-on person ... Managers who are visible, they have a much better cooperation level from their staff .... so like for the last month or two months, we're busy with renewal of contracts so I'm very, I'm very visible. [Programme manager, male, NGO linked to Facility 3].

Ironically, in the above instance, providers argued that the programme manager's visibility was to verify their attendance, upon which their employment contracts were renewed.

The facility managers varied in terms of their professional experience in a management position, approach to management and relationships with staff. Of the three facilities, Facility manager 2 was the oldest, with the longest experience as a facility manager, and had been managing the facility for almost ten years. The other facility managers (i.e. Facilities 1 and 3) were significantly younger and collectively had been in their present positions for less than three years. In addition, Facilities managers 1 and 3 continued to be involved in clinical work, although they both recognised that this fell outside of their function. Of the three managers, Facility manager 1 had the most challenging relationship with her staff:

In the records room, the facility manager is arguing with the female reception clerk over the stats. The waiting room is full and patients are observing the exchange between the manager and clerk. The facility manager is very unhappy, scolding the clerk "Stats are giving me a head-ache; you are capturing the data incorrectly". The clerk responds that she is capturing the data correctly but there is a problem with the system. The facility manager appears not to have heard the clerk, continues "From today onwards, let's work harder. Don't file any folders unless I see it. Currently we are losing out on our stats. I am not impressed really!" [Facility observations, 9 October 2012, Facility 1]

Sr [name of facility manager] embarrassed me in front of [Tb co-ordinator] and Sr [name] [TB PN] was there in the room. There was results missing of a patient. I said "But sister [Facility manager]". She [Facility manager] said "There must be no buts!", but it was very abruptly said. She [Facility manager] did apologise later but it was out like toothpaste, you know and I don't know. Off the record, she [Facility manager] swears a lot, unnecessary. And we, we go and pray in the morning ... the prayer doesn't go with us, to cover our entire day. It just stays in the staff room. [TB assistant, female, Facility 1]

What I always say to the staff is, "If you want to be treated like and adult, then act like an adult." Because my thing is I only ask my daughters at home and I only shout at my daughters at home because they're my children, you're not my children you're my colleagues. But sometimes then it feels like I need to shout at them [staff] as if they are my daughters ... And I know that is wrong, so I am working on that, I am working on it. [Facility manager, female, Facility 1]

In contrast, the relationship between the other facility managers (i.e. Facilities 2 and 3) and their staff appeared less strained, generally collegial and in some instances, friendly:

Doing the rounds with the staff, asking them how they are doing, how did you sleep; it helps them, they feel good, they feel important. Having meetings, sitting with them as the TB staff and the rest of them team, they feel important ... it is not only now about work, it's about you being a some of them say, mother (laughs) but seeing you as a supportive person and a supportive person must be able, if you want good staff they must be able to phone you even at home and say I have this challenge how do I go about it with an open door system also helps ... because if I don't respect them they won't respect the clients they will be angry towards the clients. [Facility manager, female, Facility 2]

My husband died and [name of facility manager] came to the house to sympathise and she offered me her condolences. They collected some money and then she gave it to me and she talked to the other lady that got the sponsorship from Woolworths and then she also bring me some groceries. [CCW, female, Facility 3].

### ***Institutional trust***

Institutional trust was built around expectations and experiences of working conditions, organisational culture, human resource practices and the broader TB policy.

### ***Working conditions***

Working conditions related to work load, working hours, safety and security, and the availability of resources to enable providers to perform their work.



Work load was a raised as a challenge in all three facilities. Providers, particularly nurses and NGO staff, described being expected to carry out additional functions which fell outside of their job description, limiting the time available for their own primary responsibilities:

When there is a need for you to deliver [condoms] I must just go and deliver condoms ... that becomes a problem because I must leave my work incomplete because all of a sudden, I am a driver ... I am nurse like them ... that irritates me because I leave my work incomplete and I must answer at the end of the day and] get shouted at ... I approached the [facility] manager and she ended up understanding. [EN, male, facility 2]

The TB Assistant says that in total she only earns R2000 per month for this job. As the TB assistant, she should only be following up on those who are non-compliant, doing recalls, and getting sputum tests done of those who need them. Ideally, she says, she should be out of the clinic between 9 and 12, and when she arrives in the morning there should be a folder with everything in that she needs to have and to follow up on, left for her by the PN. There should, also, she says, be an area treatment assistant, who would help her so that she can spend more time working in the records room, helping with the administration. The DOTS supporter explains that she is only meant to be the in-house DOTS person, observing those coming in to take their medication. She is only meant to be in for two hours a day. However, she also follows up on “sputums”, and fills the cups [dispensing medication]. [Facility observations, 18 October 2012, Facility 1].

In addition, in a context of staff turnover in the research facilities (Facility 1) as well in other facilities in the larger sub-district (Facility 3), an increase in workload on existing staff was inevitable. In Facility 3, this often meant that staff were deployed to other facilities in the sub-district with staff shortages:

In the staff room, two professional nurses (PNs) complain about their colleagues “being pulled into Facility [name]”. One of them exclaims “This goes against the recent policy in the sub-district that staff will not be shifted around to meet staff shortages in the sub-district!” They are clearly frustrated and upset and complain further that they are short-staffed and the workload per head increases. They reflect on the high turnover in the sub-district. It appears that a SPN in a sister facility resigned without giving a “proper notice”. They complain that “staff are burnt-out” in the sub-district and one of PN remarks “we give and give, we are entitled to take”. [Facility observations, 17 October 2014, Facility 3]

In Facility 1, the resignation and redeployment of the TB support staff (i.e. DOTS assistant and TB assistant), without their posts being filled, was a challenge for the newly-appointed TB professional nurse:

I can say the register wasn't up to date. Some of the patients' folders wasn't up to date ... some of the patient's was discharged but sputum was not done ... I needed to start from scratch and it was a LOT of work. I sometimes feel I don't want to come to work ... I said I was doing three people's work and she [facility manager] was saying to me, “Don't tell me anything about that, I don't want to hear nothing about that, if your thing must be in, it must be in.” So I said to Sr [name] [facility manager], I even went to cry at home, because *ek kan nie meer nie*. [I can't do it anymore] ... *my hand is seer van skryf* [my hand is sore from writing], because I must do the sputum, I

must do the admissions, I must do the discharges, I must see to the patients whose on NSP and I must see to those who is HIV positive and I must take the new bloods, patients who come in for MDR, when they going to doctor, I must see that their bloods is taken and all that ... this clinic need three staff members in the TB room. It was getting too much and I just decided I want to go on two weeks leave, but still when I was at home, I was still worrying about things that is happening in that clinic ... even the whole district was talking about the clinic ... Now they bringing me here now and they expect now miracles. [TB replacement PN, female, Facility 1]

Working hours were also raised as a challenge, particularly by the NGO staff located in both the facilities and the community. As noted in an earlier quote, CCWs, TB assistants and DOTS supporters were employed part-time, but were often observed working additional hours across all facilities. CCWs spoke of visiting patients in the evenings and on weekends and having patients visit them in their homes. In one of the facilities, MDT (multi-disciplinary team) meetings were held at 13h00, which was outside of the working hours of CCWs (i.e. 9-12h00):

My child is at grade R and I am required to pick the child up at 13h00 ... Our working hours are 09h00-12h00. The [MDT] meeting that starts at 13h00 ... [this] violates my right of picking up my child ... these things are hurting because if I did not go and fetch that child, I can find him lost. He is 5 years. [CCW, female, facility 2].

Providers spoke in detail of the stress related to working in communities where personal safety was a daily challenge, which challenged their ability to effectively carry out their work:

I am angry, I am being robbed. They [employer] were speaking in White man's English ... I kept on saying *ja baas* [sarcastic] ... I must go out and look for people in their houses. I go there and get lost ... [I] find a man walking around naked with his long penis ... The money we are getting is little while the working we are doing is this much [showing by hand] .... You are working for a pair of shoes that you are using to walk their entire location. When I arrive home I do not have compassion ... [TB assistant, female, facility 2].

What would happen if someone would be infected? They [management] would probably go back and say "But why didn't you wear a mask?" ... They [management] are always blaming someone else, they don't actually take accountability. The same goes for the security of the clinics. We are in a very high risk clinic and they only have one security guard per clinic; at certain clinics they don't even have a security guard, or they only have it at night time and that is to look after the building. We've spoken about this and it's never been taken seriously. [Doctor, female, Facility 3]

The first quote, besides raising the issue of inadequate remuneration, particularly for CCWs in relation to what they considered a disproportionate workload and unsafe working conditions, also raises issues of gender-based violence. Across all facilities, community-based staff (i.e. CCWs, TB assistants, DOTS supporters) were predominantly women. Interestingly, although in Facility 2, which was located in an African Black community, women reported feeling unsafe in the community, the opposite was conveyed in Facility 3, which was located in a Coloured community. In the Coloured community, the CCWs were known in the community as "sisters". Observations, informal discussions and interviews suggested that women and particularly older women commanded respect in the

community. In contrast, male CCWs were at risk of being perceived as either undercover policemen or gangsters and seldom worked in the community alone:

I think that females are more vulnerable than males within the community. But I think that female CCWs carry more or command more respect than males within our community ... So, I think a male would go and knock and they would think that it's the policemen that is at the door. [Programme manager, NGO, male, Facility 3]

They respect women. There again the women play big role. They [community] identify you by the clothes you having on. You find them [gangs] on the corner you, you just [say] "hey hello good morning, how are you doing today?" They [gangs] say "Alright Sister. And Sister?" [Provider responds] "No I'm fine. I'm looking for number 100". "Sister no this is 89, further down Sister, no there, there's no dog, Sister". But when you are man and you ask them they think you one of the gangsters come do undercover work in the area. It's risky for a man. [TB assistant, female, Facility 3]

One of the consequences of this was the CCW's always worked in pairs, and they shared stories of how they assisted each other in the field, particularly with challenging clients who were either difficult to locate or posed a threat to their personal safety. In Facility 2, the male CCW in particular was recognised and appreciated for his willingness to take over difficult patients from other CCWs.

For those who worked out in the community, a related challenge was management's lack of empathy for the challenges they faced in working in unsafe environments. A CCW described the response from management as unsupportive and unsympathetic when her phone was stolen during a visit to a patient in the community (quote 1 below):

I didn't get nothing. The only thing that they [management] told me "Yeah we told you not to take your phone with you" ... They [management] don't give you airtime but they expect you to kind of like make appointments with your patients. [CCW, female, Facility 3]

But uhm, it is dangerous in general even besides the places that I go because I can get robbed. I sometimes use my money and I travel with the taxi, or otherwise ... [TB assistant, female, Facility 1]

The only people who are enjoying butter and jam are the ones in here. We out there are slipping into something I cannot mention, do you understand? Instead of being caressed when you come back because I have slipped badly out there you find that the real whip is here. There is no support. When you return tired after coming from looking for people, you are told you are not working ... I mean it makes me feel down. [CCW, female, Facility 2]

As raised in the first quote, providers across all three facilities were observed using their personal phones to contact patients, without being reimbursed for the costs. CCWs without airtime or money for transport often incurred more time in following up patients on foot, and were inadequately protected during winter (rain) and summer (heat):

CCW1: Give us transport money ... Because we have to walk very, very far and the other thing is that ...

CCW2: And because it's hot ... It's hot, you don't have a hat ...

CCW 1: And the winter you know how many times I got wet and then you ask “Isn’t there a jacket?”. They [management] say they are going to get jackets but they don’t have, or if they have if they get jackets then it’s for the ...

CCW 2: Counsellors. It’s like they get the first preference but they work in doors the whole time [laughter]. While we are supposed to get wet, everything we are not supposed to get anything, but I mean you are first supposed to think about those in the field and I feel that this uniform is not appropriate for us on the fact that we walk. We are supposed to get tracksuits or something ...

CCW 3: Or a sweater ... Or something because we do all the walking and when it is raining we have to walk. We don’t get money for when it rains, we get sick [laughs]. We talked about it, we spoke about it at the meeting and they [management] said we are going to get but ...

CCW 2: Nothing. We still are hanging ... We didn’t get anything yet we are still hanging.

[FGD with CCWs, Facility 3]

In addition, poor resources and infrastructure within facilities also challenged the ability of providers to carry out their work. For example, doctors and nurses depended on laboratory test results from National Health Laboratory Service (NHLS) to be able to make decisions on when to initiate patients onto treatment, change their treatment from the intensive to the continuation phase, or change the treatment in the case of side-effects and drug-resistance. However, delays in receiving the results from NHLS hampered their ability to provide responsive and appropriate treatment. In addition, the lack of infrastructure like a computer in the doctor’s room, which provided access to laboratory results, were equally frustrating:

The fact that it is so difficult to get normal things like blood results; it is very irritating for me to walk every time to their [records room] office and the computer doesn’t work ... we should have a computer. I don’t necessarily need a computer here but we should have a computer in the TB room ... It is very high in the priority list in South Africa. Why don’t have computers? The City spends a lot of money on IT but our computers are at a standstill. It is very time consuming, waiting for someone to fax you the results ... sometimes you’ll see three pages for the same results ... we’ve spoken about this before but this is the agreement that they had with the lab [NHLS] but even simple things like the phone is not working. If you think about it, sometimes I have to go to the front, it’s five minutes that you could have seen a patient. [Doctor, female, Facility 3]

Despite these challenges, some providers appeared to be willing to take on more as an opportunity for recognition, promotion and personal growth:

I am working so hard I am trying to prove a point also to my seniors that I can take a challenge so that maybe something better can come up for me, I am selling myself. [CCW, male, Facility 2]

Sometimes it just comes to that point that you must work out of your capacity. If a manager tells you something that is not in your scope of practice there’s a reason why she tell you do that; because you can grow or stay there where you are. [EN, female, Facility 3]

### *Human resource management practices*

Human resource issues related primarily to salaries, mentorship and support, and opportunities for professional growth through training opportunities.

With the exception of doctors and professional nurses, inadequate salaries and stipends (with respect to CCWs and DOTS supporters) were an issue raised by all other staff across the facilities:

You see, once you go to remuneration [laughter] I tell you, it makes me mad because remuneration sometimes in my sleep I tell myself that the way I work but there is nobody who says thank you. Firstly, you are working for a cent. Secondly, at the end of the year there is no thank you. No bonus. We used to have bonus but since last year we did not have bonus again. The reason I don't know. We even asked there at [name of NGO] whether they have someone who is a funder. Working as a fundraiser? They do have but is struggling to get funds. But the way I see it at my NGO there are new cars. There is nobody who cares for the counsellors. We are working because we love our work and we think of our patients. [TB adherence counsellor, female, Facility 2]

The money [stipend] should go up a bit because there's a lot in this money that we have to buy airtime also which is they do not provide for us, you understand? We get R1445.00 [stipend] and the responsibility of Aunty [name of fellow CCW], she have to look after two babies, she have to get grocery, she have to get everything like .... I have to pay crèche fees; I have to I also have to look after my sick mommy ... I'm the only one working in the house. Okay I'm not trying to make that their problem but they should just boost the salary up a little bit. [CCW, female, Facility 3]

Despite the challenges of poor salaries, training opportunities and supportive supervision, which were identified by both facility and community-based providers, were regarded as important for building confidence and knowledge in their work, and were also seen as an opportunity for growth:

There's meetings, we've got our coordinators they come around to the clinics ... [I] can tell them what I don't understand and they teach [me] and they sent us for training. [EN, female, Facility 2]

We all had an opportunity last year to go to study as counsellor[s] at Groote Schuur [Hospital]. And so this year we are doing a project. I'm not the counsellor, I'm a CCW but I have to go phone the client, the way the counsellor do with the client. And that is very challenging because everybody that is in the class with me are counsellors. I'm the only one that is a CCW. So I appreciate what they are doing and that motivates me [CCW, female, Facility 3]

In contrast, poor mentorship and support undermined the confidence of providers to fulfil their professional responsibilities:

I was like really literally thrown in the deep end, so I told her [facility manager], she's really expecting a lot from me for someone who hasn't worked in the TB room ... I told her I am willing to, to learn but it is a big responsibility because it is a huge area, you know ... if I worked hand in hand with someone in the TB room, that someone who could mentor me [but] I was working, in the TB room, it was you can almost say by trial and error, that obviously didn't work. [[PN, female, Facility 1]

Our mentoring sessions has been taken away ... we haven't had mentoring for about three years now. And I think that is what we need ... when we had it, she [mentor] was a fantastic lady and you could really feel when you left there that it helped, you felt better. So I do think that is a big one for, for us as counsellors, we need debriefing, need mentoring yes ... [Adherence counsellor, female, Facility 3].

#### *TB Policy and service delivery context*

In relation to TB policy, providers highlighted the issue of performance indicators, and in particular target setting and the related administrative burden, as key challenges which affected them and specifically their ability to carry out their work:

Everything is about these stats ... If a target is being missed you have to come forward with an action plan to meet the target. The sub-district manager wants his sub-district to look good otherwise he is told he is a bad manager. [PN, female, Facility 1]

Eish these policies, some of them are on stats and stats is based more on paper work than it is on clients, so you end up polishing your work on paper more than what it actually is because City wants its target no matter how you do it. If City wants 600 then we must make 600, no matter how we do it because really at the end we were supposed to balance the targets with the clients, but the main thing is the client ... [EN, female, Facility 2]

So we put in systems in place and I told management "Miracles is not gonna happen now. I will reach that cure rate but just give me some time, and it's not always about stats and the cure rate I must reach, it's about my patient" .... [EN, female, Facility 3]

As highlighted in these quotes, the demands of target setting impacted adversely on providers. Besides considering it stressful, they also felt that it was prioritized over patient care. Moreover, as suggested above and explicitly stated below, providers felt that management and policy-makers made decisions without consulting them:

I am going to be honest, whoever comes to decision-making, when it comes to the Department of Health, if I may say so, I won't say they don't know what they are doing, but to us counselors it's not good to us. For an example, we used to test people each and every three months right? Of which the target 12 per day, that's fair okay, it's alright we can reach the target, and all of the sudden they change it to six months expecting to have 12 patients a day, does that make sense? If you are a bird and flying up there you kind of like not seeing what we are doing here in the ground, you will make rules that you think are better for us because they kind of like change rules. This stats thing, it's driving me crazy I am not saying they must do better, but I think if ever they are going to make a decision about us they should have someone like us to help them make the decision about our decision. [TB adherence counsellor, male, Facility 2]

In some instances, the challenge of target setting and related statistics impacted negatively on relationships between management and staff and overall on staff morale, particularly in Facility 1:

The afternoon with Sub-district TB co-ordinator did not go well. We were accused of not having all the stats up-to-date. [Name of TB assistant] mentioned that there was a problem with the computer and clinic [facility manager] manager said that she did not want to hear any 'buts'. [Name] was crying. I was thrown in the deep

end; I have not worked in TB previously. They don't realise how long a TB observation takes, preparing patients, taking their history, adherence counselling. In between, there are calls for referral, follow-up on defaulting clients, calls to NHLS. Which are more important, people or paper? [Professional nurse, female, Facility 1]

In the context of a large MDR TB load and TB-HIV co-infection (Facilities 2 and 3), providers complained of the administrative burden and described their overall experience as 'draining and tiring' and being 'over-worked':

Once the patient is started on normal TB treatment, I will notify in the register. It's also a lot of information that they want in there. What kind, how the sputum was, what type of specimens were taken? They want all of that, whether it's a smear positive or a smear negative; they want all of that, if the patient is HIV positive they want to know. Has the client started on ARV's and how obviously how the patient was diagnosed? Was it now with CSF, X-ray, chest X-ray or sputums? But most of the times sputums, yes we do the gene-expert and we do the smears. Yes, and also you would look at your defaulters in the afternoon, get that ready for the next morning so that they [defaulters] can be followed up. Even though recently they've put the EN to help me out, I still manage, I have to manage the TB room and also the administrative work, all of that, all the problems, bloods, tests. With the MDR's it's all my responsibility so it's increased a lot. I'm drained, tired yes, just over-worked. You know I would actually stay in the TB room but just with that extra help because I enjoy doing what I'm doing there. [PN, female, Facility 2]

While the above was the experience of most of TB providers, there were exceptions who believed that working towards targets was motivating and that the workload was manageable once there was a system in place:

Targets make us able to do our job because when you don't have targets you become relaxed so they make us eager to do our job. [PN, female, Facility 2]

This is how I survive in the TB room. Number one is your personality and attitude. I've got experience of patients that comes to our facility ... They default the treatment and the way I approach them; the way I give the counselling because your first contact with the patient when they start the treatment that patient can draw a picture for you. And number two is you must know your TB control programme. You must know when to do sputums, you must know what are the outcomes and you must know all about TB. And number three, very important is systems. You can have a 105 or 500 patients or even five patients, but if your system is not correct, and nobody can work out a system for you only you yourself. And the end of the day you can sit the whole day in the TB room but the end of the day that table must be clear. [PN, female, Facility 3]

Across all three facilities, NGO staff narrated ways in which they did not feel completely included in the organisational life of the health facilities. For those who were located within the facilities (i.e. counsellors, TB assistants etc.), although they described having collegial relationships with City staff, demonstrated through participating in rituals (e.g. morning prayer) and taking breaks together, they often narrated instances of organisational practices which left them feeling excluded:

I go to the staff room and then I make me coffee ... then they [City of Cape Town staff] came and tell me “No you can’t have coffee, that is not the [NGO’s] coffee that is the City.” And I said “Okay, what does that have to do because we are all working together we are all the same.” I asked the Facility Manager and then she said, we are entitled to have coffee, “Just the coffee, every time you come here you work, you are part of the clinic, you may make a cup of coffee, but you can’t use the milk because they only give a certain amount of milk.” I understand that we can’t have the same privileges that they have because we are not from the same whatever NGO or and they for the government ... but at the end of the day you, your stats are going up because of us. We are working as hard as other people and then when you need help; you always come to us ... [CCW, female, Facility 3].

No I do not have a problem here at the clinic because when you come to [Facility name] you come to people who are approachable but my problem is the City. Since we are working here, we are like working for the City but when City has functions, only calls her staff. You as an NGO person she [Facility manager] does not know you, she just looks at you and does not want to see you. If there is a staff outing, she [Facility manager] will pay for her staff. She knows the number of her staff. She has nothing to do with you NGO people but we are working for City. [CCW, female, Facility 2]

### ***Outcomes of trust in colleagues and management***

As described in the previous section, trust operated at the interpersonal and institutional level. A cross-case analysis of outcomes of provider trust (interpersonal and institutional) is summarised in Table 7.7 below. Consequences or outcomes of provider trust were developed inductively and deductively. Inductive codes which emerged included for example seeking alternate work. The literature on organisational trust (Gould-Williams, 2003), and specifically human resources for health (Okello and Gilson, 2015; Topp and Chipukuma, 2016) and analysis of consequences or outcomes of interpersonal and institutional trust in the workplace, was drawn on for the deductive analysis.

Importantly, when trust and specifically interpersonal trust was present, it led to co-operation among the TB team (Table 7.7). When institutional trust was challenged, providers spoke of a need to seek alternate employment. The implications of this in the context of primary care teams and the implications for patient trust in providers will be explored in the discussion.

When interpersonal trust, built on supportive and enabling interpersonal relationships with colleagues and team members was evident, it enabled and maintained co-operation and team work. Similarly, when interpersonal trust in management, built on experiences of managers and supervisors as respectful, caring and empathetic, was evident, providers’ attitudes towards management were positive and appreciative. Acts of recognition of the challenges (e.g. Facility 1 District manager responding to the PN complaint regarding workload and burnout) and effort were experienced as demonstrations that management was caring, and recognised them as individuals beyond their professional roles.



When providers felt that they were appreciated and recognised, besides being motivating, it was also reassuring that management acted in their best interests:

I never think that they [management] taking advantage of me. Like management will always tell me “You do again good in TB or you again 100% [TB cure rate]”. Like yesterday our manager had a meeting with us, just the TB staff that’s working in the TB room. And she will always say “thank you for what you do” and we appreciate that. I always think what that person [manager] think of me so I don’t want to disappoint people because of what they think of me. [EN, female, Facility 3]

**Table 7.7: Outcomes of trust in colleagues and management**

	Outcomes of trust	Outcomes of distrust
<b>Providers behaviours and attitudes</b>	<b>Interpersonal trust</b>	
	<ul style="list-style-type: none"> <li>• Co-operation among TB team</li> <li>• Positive attitudes towards supervisors and management</li> <li>• Appreciative of management</li> </ul>	<ul style="list-style-type: none"> <li>• Negative attitudes towards supervisors and management</li> </ul>
	<b>Institutional trust</b>	
	<ul style="list-style-type: none"> <li>• Perceives employing organization uncaring and connected</li> <li>• Motivated to work harder</li> <li>• Motivated to remain with the facility</li> </ul>	<ul style="list-style-type: none"> <li>• Perceives employing organization as uncaring and disconnected</li> <li>• Feels demotivated and unhappy</li> <li>• Seeks alternate work</li> </ul>

In contrast, poor interpersonal trust in managers and supervisors, built on several instances of negative interactions and being criticised for poor performance (see page 142), contributed to them feeling unsupported, disempowered and overall demotivated:

Some days, I just want to give up. I threaten to leave multiple times a day ... but I tell my daughter that if I quit there are no ballet classes and less fun things. [TB assistant, female, Facility 1]

Institutional trust, built on expectations and experiences of working conditions, human resource practices and the demands of the TB policy and service delivery context, was experienced differently by different cadres of providers. NGO staff located within facilities and the communities had the poorest experiences relating to all dimensions of institutional trust, leading them often to question the trustworthiness of management, and the larger administrative structure in which it was embedded as not always acting in their best interests nor recognising the personal risk embedded in

their work. In the context of poor institutional trust, several providers particularly CCWs admitted looking for alternate employment. At the same time, it was not evident that this affected their performance and relationship with patients. Interestingly, facility observations and interviews with patients indicated that providers, who were often the most demotivated, remained committed to patient care.

These caregivers based in facilities are partially supervised by health facility staff (e.g. professional nurses) in addition to their NGO managers, contributing to ambiguity in line management and challenges when facility and NGO differed in their direction. Examples of differences included a dispute when a facility manager insisted that 'lay counsellors' should remain in the same facility and build up long-term relationships with clients, whereas the facility manager wished to have the flexibility to shift counsellors among facilities depending on workload and staff shortages.

### **Concluding remarks**

In summary, providers' experience and ultimately trust in patients, management and their employing institution was shaped by individual factors, perceptions and experiences of patients' trustworthiness, and institutional factors. Individual factors, and specifically professional status, were an important influence on provider experiences and their relative power in relation to both patients and management. With respect to patients, providers' expectations centred primarily around treatment adherence, respectful engagement and recognition. Experiences of patient trustworthiness was patterned on professional hierarchies which conferred respect and professional boundaries. Similarly, management recognition and the provision of a safe and enabling work environment also followed the fault lines of professional hierarchy. This meant that providers articulating the most vulnerability, uncertainty and risk in their lives were those lowest in the professional hierarchy, with differential implications for outcomes of trust in patients, colleagues and management.

*For it is mutual trust, even more than mutual interest that holds human associations together*  
(Mencken)

## **Chapter 8: Discussion**

The study set out primarily to explore how trust is built and experienced between patients and healthcare providers for TB treatment in primary care settings, and the influence of gender on those relationships. The literature on this topic, and specifically with respect to South Africa and other LMICs is limited, motivating the need for this study. The key empirical findings have been described in detail and summarised in the previous chapters. This chapter will synthesise the findings to answer sub-research questions and the overarching research question in relation to the broader literature.

More specifically, the discussion will comprise two parts:

Part 1 will reflect on the findings in relation to the sub-research questions with respect to the relevant literature. As a reminder, the research questions were:

Question 1: Do the flows of trust between patients and providers influence treatment adherence and how?

Question 2: What builds trust for male and female patients in healthcare providers for TB treatment in primary care settings and how are they different?

Question 3: What patient-related and institutional-related factors build provider trust in patients?

Part 2 will conclude the discussion reflecting on the overarching research question (i.e. How is trust built and experienced between patients and healthcare providers for TB treatment in primary care settings and how does gender influence those relationships?).

### **Part 1: Findings in relation to research questions**

#### ***Question 1: Do the flows of trust between patients and providers influence treatment adherence and how?***

This study has found that mutual trust between patients and providers, built on assessments relating to competency and interpersonal communication, enabled adherence and the quality of the patient-provider relationship. Consistent with the broader literature on adherence to anti-TB treatment, this study has also confirmed that treatment adherence is influenced by a range of personal and contextual factors, operating at the community and health delivery organisational level. Personal

factors or vulnerabilities influencing adherence included socio-economic status, access to psycho-social support and gender. At the broader health system level, complexity of treatment, accessibility of services and relationships with healthcare providers were important influences on treatment adherence, confirming other studies of challenges for TB adherence in South Africa (Dick, 1999; Naidoo and Mwaba, 2010; Naidoo *et al.*, 2013; Churchyard *et al.*, 2014). Further, interactions among these factors lead to acute vulnerability, often severely challenging the capacity of patients to adhere to treatment.

At the same time, for some patients, even when access to social support, positive relationships with healthcare providers and interventions for reducing or even eliminating the financial barriers to accessing care were present and beneficial, these were insufficient and ineffective in the absence of patient motivation. As evident from the findings, patient motivation, often linked to gender roles (e.g. need to be cured and healthy to provide for dependent family) and norms (e.g. wanting to look healthy and physically attractive) – either pre-existing or instilled through intensive formal counselling and encouragement from healthcare providers – was essential for treatment adherence. The present study provides examples of patients with pre-existing motivation adhering to treatment, despite being acutely vulnerable, and in some instances, experiencing the services and healthcare providers as unsupportive and uncaring. However, for many of those acutely vulnerable, motivation emerged as an outcome of trust in healthcare providers in the treatment process, built and sustained through intensive counselling and continuing support and encouragement, particularly on the part of CCWs, with implications for treatment adherence.

Trust in healthcare providers - founded on a combination of technical competence, interpersonal communication and responsiveness to patients' unique needs - was a powerful influence on motivating patients to commit and adhere to treatment. This was particularly so for those who were acutely vulnerable and socially marginalised. These findings support previous research that has examined the influence of vulnerability and interaction amongst its dimensions, including nature of illness, gender, race and socio-economic status, on trust and treat-seeking (Sheppard *et al.*, 2004; Riewpaiboon *et al.*, 2005). Further, trust constructed on the basis of providers' willingness to acknowledge and exercises of sensitivity in responding to vulnerability based on socio-economic status and gender, in addition to providers' technical competency and patient trust in the broader healthcare institution (e.g. provider ethical and moral standards, fair and equal treatment of all patients), were critical for building motivation. This finding was supported by the broader literature on the influence of trust on treatment seeking behaviour (with implications for motivation) for diverse health conditions (Sheppard *et al.*, 2004; Skirbekk *et al.*, 2011; Murray and McCrone, 2015).

While the above discussion speaks to a uni-directional flow of trust from patients to providers, what was the effect of provider trust in patients and more importantly, bi-directional or mutual trust between patients and providers on treatment adherence? Previous research indicates that mutual trust between patients and providers reduces the need for monitoring the behaviour of the other and is important for building cooperation (Cook *et al.*, 2004). While patient-provider dyads were not explicitly studied, triangulating from both provider and patient interviews indicates that mutual trust, built on competency, recognition and acceptance of mutual vulnerability and respect, not only enabled adherence, but also improved the quality of the patient-provider relationship and their overall respective experiences. Mutual trust reduced tension which often arose from suspicion over the other's motives. For instance, mutual trust emerged under the following circumstances.

Providers believed that patients were motivated and cared sufficiently about their own health to adhere to treatment and that their efforts were recognised and appreciated. Patients believed that their health and well-being mattered to the providers. While not eliminating the inherent power differentials, relationships of mutual trust were characterised by shared decision-making over the treatment regime and a corresponding absence of tension and suspicion in the relationship over the motives of the other. Mutual trust enabled the building of inter-personal relationships, demonstrated through mutual exchange of information and sharing of personal stories. As noted by Mencken, "For it is mutual trust, even more than mutual interest, that holds human associations together." This was demonstrated in Facility 3, where male patients were permitted to take their treatment as a group. The provider recognised that gender norms of masculinity challenged adherence, and demonstrations of empathy and creative methods for reducing challenges for access built trust in providers and enabled treatment adherence. The provider also indicated interpersonal trust in the group of male patients, based on their respect of professional boundaries.

Moreover, as Rogers (2002, p.77) argues in defence of providers trusting patients and in fact arguing that it was a moral duty, 'A willingness to trust can be seen as morally valuable because trusting another person involves treating that person as a moral agent ... A refusal to consider a relationship of trust precludes treating the other as a moral agent by denying them the opportunity to demonstrate responsibility, thus reducing the other to object-like status'. When patients perceived that they themselves were regarded as trustworthy by healthcare provider, demonstrated through a combination of commendations and a willingness to accommodate patient needs, this was a powerful motivator for treatment adherence. These findings are consistent with work by Robinson (2016, p. 9), who argues in a paper on trust in the context of chronic illnesses, that recognition and 'affirmations are have been noted to support collaborative health care relationships'.

**Question 2: What builds trust for male and female patients in healthcare providers for TB treatment in primary care settings and how are they different?**

In answering this question, it is important to restate the definition of patient trust as applied in this study. Patient trust is the confidence or the positive expectation that the health care provider, and the health system which they represent, works for the best interests of the patient and has the technical and personal competencies to do so.

This study of patient trust in healthcare providers in different TB primary care settings affirms the findings of earlier studies that trust is relevant for building and maintaining therapeutic relationships between patients and healthcare providers. Further, the evidence from this study suggests that patient's trust in providers was influenced by three key factors. These factors included: patient vulnerability; provider attributes which have a bearing on assessments of providers' trustworthiness; and organisational context of TB service delivery. While these factors are discussed below separately, it is important to recognise that they are inter-connected, suggesting that the pathways of trust are complex and the outcome of multiple of influences.

***Patient vulnerability, gender and trust***

Similar to previous studies (Kagee and Martin, 2010; Fried *et al.*, 2015) participants' vulnerability was not limited to experiences of the disease (i.e. TB and even TB/HIV co-infection). Vulnerability was shaped and deepened by complex intersections of factors operating at the personal (i.e. socio-economic status, psycho-social, gender, and specifically social roles and HIV co-infection) and wider community and contextual levels which included stigma and living in economically marginalised townships in Cape Town (See Chapter 5: Challenges of poverty, crime and violence in communities). As described in Chapters 5 and 6, these townships are marked by widespread poverty, unemployment and social problems including violence and gangsterism. Participants who reported multiple and simultaneous material (i.e. poverty, unemployment, food insecurity, dependents) and psycho-social (i.e. stigma, absence of social support, lack of motivation to live and emotional distress) challenges could be described as *acutely vulnerable*. These findings confirm previous studies in South Africa, that TB and TB/HIV co-infection, can for people living 'on the social and economic margins of society ... put a strain on family, friends, and wider social networks, often through illness-related stigma, prolonged reduction of social activities, and a strangle- hold on financial resources because of additional expenditures (and often reduced income)' (Fried *et al.*, 2015, p.631).

The importance of psycho-social support in a context of acute vulnerability has relevance for the findings of this study. While this research did not set out to investigate mental health among

patients with TB, the findings indicate that despair, hopelessness and dejection - suggesting poor mental health - characterised acutely vulnerable patients living with TB or TB/HIV co-infection. This is not surprising, given that previous studies in South Africa (Kagee and Martin, 2010; Peltzer *et al.*, 2012; Fried *et al.*, 2015) and elsewhere (Duko *et al.*, 2015) have pointed to anxiety and depression as important and highly prevalent mental disorders in patients with TB and TB/HIV co-infection. Equally concerning is that there is also substantial evidence showing that mental health disorders are associated with poor treatment adherence (Mayston *et al.*, 2012; Uthman *et al.*, 2014).

In the present study, gender emerged as an important source of vulnerability and associated experiences of disempowerment. For both men and women, vulnerability was a complex outcome of gender, socio-economic and psycho-social factors. Gender - in terms of access to resources (e.g. link to social networks including family and friends), social roles (e.g. responsibilities arising from being the household head, child-care) and social norms (e.g. facilities being equally comfortable for men and women, availability of male and female healthcare providers) - not only challenged access to treatment, but also shaped patient expectations. For women, vulnerability arose primarily from their roles as heads of households and primary care-givers of dependent children. Male vulnerability was influenced by comparatively poorer access to social networks, conflict between their treatment and work, role as the head of the household and the challenges relating to being male in a health facility. As Morrell (2007) reflects specifically with respect to men in South Africa, that although they (i.e. men) typically occupy higher positions of social status compared to women, however their experience of power and privilege is far from uniform.

Why is this discussion on patient vulnerability, including dimensions of gender and mental health, relevant for trust in healthcare providers and the health system? This is because the findings from this study indicate that needs and expectations of participants who were *acutely vulnerable* of the health services and healthcare providers, were often higher compared to those relatively less vulnerable. Moreover, the needs of those acutely vulnerable, frequently extended beyond the disease and therapeutic relationship, to include economic and psycho-social needs (Hall *et al.*, 2001). This has implications for trust. As Offe argued (1999, p. 55), 'those lacking resources (power, wealth, information) cannot afford to trust, as misplaced trust is feared to have disastrous consequences from which actors are incapable of protecting themselves through other means ... The apparent paradox is that those who are most in need of trust-based relations, cannot afford the risk involved ...'. Flowing from this and of relevance for the findings of this study, it can be argued that for the acutely vulnerable, the higher the need or potential for trust and by implication, the higher the risks.

Trust involves risk, because by trusting, the trustor (i.e. patient) become dependent and vulnerable to the trustee (i.e. healthcare provider), while expecting that the trustee will respond to their needs and act in their best interests. Trust and vulnerability have a bi-directional relationship, where trust can only exist in the context of vulnerability and ‘... trust is an outcome of vulnerability’ (Pilgrim *et al.*, 2010, p. 85). As evident from this study, when patients’ expectations were not met, and in some instances violated, not only were patients disappointed and often distressed, but existing vulnerabilities and experiences of disempowerment worsened, challenging the emergence and/or, continuation of trust. Therefore, for acutely vulnerable patients, trust was risky.

This assertion that trust is built in a context of where it is safe to be vulnerable, links to an important finding that arguably for many participants, motivation to seek care was guided by pre-existing trust with respect to providers or the health services. The findings suggest that for some participants, previous poor and disappointing engagements with health services had contributed to pre-existing distrust. In such instances, dependency and even desperation (and not trust), characterised by a lack of options, compelled the decision to seek care. However, in the process of expectations being met, supportive and affirming relationships being built between providers and patients and most importantly leading to improvements in health, dependency (and distrust) gave way to trust. As Gjengedal *et al.* (2013, p. 136) argue, ‘The way we are met by other people seems to be crucial for our experience of vulnerability; our relationship with others may increase as well as decrease the feeling of being vulnerable’. It is not surprising then, that assessment of healthcare providers and institutional trustworthiness were important predictors of patient trust.

#### *Provider trustworthiness*

As a reminder, drawing on a definition by Bak and Askvik (2005, p.10), trustworthiness may be understood as a ‘judgement about the level of risk involved in placing trust in specific individual or institution, and is rooted in demonstrated behaviour, reputation and appearance’. The findings from this study are consistent with and support previous work on trustworthiness of providers in the following important respects. First, provider trustworthiness is an antecedent of trust (Mechanic and Meyer, 2000; Østergaard, 2015) in that assessments of a provider’s trustworthiness enabled and built patient trust in providers. Second, judgments of providers’ trustworthiness flow from cognitive and affected-based experiences and assessments of technical competency (e.g. performing a physical examination, responding acceptably to questions on side-effects) and interpersonal communication (e.g. recognizing patients by name, demonstrations of care and empathy). Third, as described in the previous section and in the findings, patient trust in providers was built through connection and empathy on the part of providers, requiring extending beyond the immediate



disease and treatment to the socio-economic and psycho-social dimensions of vulnerability. Fourth and in the context of acute vulnerability, as Østergaard (2015) observed, providers' exercise of power in the patient-provider relationship, especially with respect to involving the patient in treatment decisions, was an important influence on assessments of provider trustworthiness. Finally, and linked to the previous inferences, trust is dynamic and fragile and as Flores and Solomon (1998, p. 223) argue, 'trust may be broken by day-to-day encounters, such as failing to keep promises or commitments, not only grand acts of betrayal'. This is particularly relevant and critical in the context of TB, where treatment entails engagement with multiple healthcare providers over a long period (Tupasi *et al.*, 2016). Consistent with the literature exploring patient-provider trust with respect to other health conditions and services across a range of contexts (Birungi, 1998; Ward and Coates, 2006; Brennan *et al.*, 2013), when patients believed that providers cared for them, affect-based interpersonal trust was nurtured and grew.

The findings from this study deepen and extend previous work on provider trustworthiness in three important areas. First, assessments of providers' trustworthiness, in addition to being constructed along dimensions of technical competency and interpersonal communication, was also built on providers' *responsiveness* to patients' needs and expectations, suggesting an affective as well as rational and calculative basis for trust. Second, trustworthiness was assessed not of a single healthcare provider, but multiple providers within the TB and TB/HIV team, with patients often reflecting that the nature of relationships and assessments of providers' trustworthiness varied depending on who the provider was. Third, in the context of long-term care for TB, assessments of trustworthiness were constantly being interrogated and tested in an evolving relationship with a team of healthcare providers, which was sensitive to the patient and the organisational context.

With respect to a complex health condition such as TB, requiring equally complex interventions and input from multiple healthcare providers (both clinical and non-clinical), assessments of trustworthiness were also multifarious. This was even more challenging for patients who were TB/HIV co-infected, where side-effects and pill-burden were identified as challenging for treatment adherence. Patients' expectations of clinical providers (i.e. nurses and doctors) differed from their expectations of non-clinical providers (i.e. CCWs, administrative staff). Regarding doctors and nurses, patients had higher expectations of technical competency relative to interpersonal competencies. With respect to non-clinical providers, and specifically CCWs, they had higher expectations of interpersonal competencies, particularly those relating to psycho-social support. The literature indicates that trust built on expectations of psycho-support including empathy are more easily fostered in relationships where providers are similar in identity (i.e. gender, language, race, caste

etc.) (Tarrant *et al.*, 2003; Sheppard *et al.*, 2004; Myburgh *et al.*, 2005). With specific reference to South Africa, Nxumalo (2016) points to the role of CCWs as important for promoting trust in healthcare providers, because of more contact between them and the patients.

Trust constructed in the context of vulnerability was empowering and motivating in instances where providers were supportive and willing to engage beyond the immediate needs of the disease, and engage with the person and their wider concerns. As discussed previously, patients' needs often extended to psycho-social support, and were in many instances gendered in nature. For example, trustworthiness of providers in Facility 1 was established based on the care and technical competency providers demonstrated with respect to a diabetic child of a TB patient. Other studies, focusing on healthcare access and relationships of trust between providers and vulnerable groups (e.g. African American patients by Armstrong *et al.*, 2008; survivors of intimate partner violence by Battaglia *et al.*, 2001), similarly found that responsiveness of providers to patients' needs, demonstrating care and empathy, nurtured trust on the part of patients. In this study, it was not surprising then to find that patients experienced some members of the TB healthcare team who were sensitive and responsive to their needs as trustworthy but not others.

Rather, the challenge for the emergence of trust was when providers (particularly facility-based) resisted shifting from a more hierarchical and paternalistic approach to a more people-centred one, characterised by shared decision-making and partnership between providers and patients. As Cook *et al.* (2005) reasoned with respect to building trust in unequal relationships (e.g. patients and clinical staff), it is incumbent upon the more powerful party (i.e. clinical staff) to recognise, respect and treat fairly the relatively less powerful party (i.e. patient). This approach was evident in the present study, where the construction of trust in providers was built on recognition of the patient beyond the illness and as a person; *acknowledging and responding* to their personal, often gendered challenges in the therapeutic relationship; and trusting the patient. As Østergaard explains (2015, p. 1048) 'A health care encounter can be a complex social situation. Here trust operates as a way of solving the problem of the power gap without eliminating it'.

In contrast, with respect to non-clinical staff (i.e. CCWs), who often lived in the same communities as patients, and where social distances and hierarchy were considerably less, affect-based relationships, constructed on psycho-social support, affirming communication practices, emotional equality and providers extending themselves beyond their job-function (e.g. collecting patients' medication from the health facility), were central for establishing their trustworthiness. This suggests an identification-based trust, similar to Seligman's trust (Seligman, 1997) as familiarity and affective - trust is based on shared social bonds, values and identity. While CCWs were employed

part-time and they often complained about the challenge of balancing patient care with their personal responsibilities, they were, compared to facility-based clinical staff, often perceived as being more accessible and more willing to spend time with their clients.

As Sheppard *et al.* (2004) argue in a study of low-income women accessing community-based public prenatal care programmes and their relationships with different healthcare providers, patients trusted lay-health workers (LHWs) more than clinical staff (i.e. nurses) for several reasons, including the willingness to spend time with them. Other reasons were the fact that their relationships were characterised by emotional equality and similar life experiences, which together contributed to providing a continuity in relationships with patients.

Continuity of care is arguably severely challenged in a healthcare system under-pinned by task-oriented care and, specifically in the context of TB and HIV care, where there are multiple providers, each serving different, but in some instances overlapping functions. For instance, in all facilities (see Chapter 5: Providers of TB services), TB assistants were employed and their key role was to conduct home-visits, recall patients who tested positive for TB and sputum tests, and follow-up on patients who were non-adherent. These functions were also carried out by CCWs. Moreover, in Facility 2 with integrated TB and HIV services, in practice services continued to be provided still separately by TB and HIV providers. This contributed to poor team function characterised by fragmentation of care, with patients interacting with multiple providers. Patients who were co-infected and required intensive adherence counselling interacted with more providers (HIV and TB counsellors, HIV and TB professional nurses, enrolled nurses, CCWs, TB assistants) than those with a single infection. CCWs were the only providers who supported both TB and HIV services. Under these circumstances, holistic care is potentially undermined, where the ability of patients to identify a single healthcare provider as solely responsible for their treatment is challenged. In this study, factors necessary for nurturing trust in providers were in many instances absent, particularly in facility-based clinical staff.

The above discussion on lack of cohesion in team function underscores the critical role of CCWs as the link between community and the formal health system, and ensuring that in those instances when relationships with some providers were challenging, relationships of trust with other providers provided continuity of care and treatment adherence. These findings resonate with those by Nxumalo *et al.* (2016) in a study of CHWs in two provinces in South Africa. The authors argue that in a context of lack of trust in government services including health, especially among socio-economically vulnerable communities, CHWs can restore trust in the health system through filling a gap for services which the health system is unable to do. Confirming the findings in this study, Nxumalo *et al.* (2016, p. 68) found that '... CHWs work to re-build this trust by establishing personal

relationships with their clients, spending time with them, and providing simple care of the kind that might be administered by kin and neighbours in other contexts. Community level health workers elicited trust through their language of communication, modifying messages in ways appropriate to the needs and priorities of the communities instead of using the language of clinical health practitioners’.

#### *Organisational context of TB service delivery*

This study has demonstrated that while patient trust was primarily anchored in and built through assessments of providers’ trustworthiness, these assessments were often tested, reinforced or undermined by the organisational context and institutional arrangements. Patient load and spatial arrangements including waiting areas also had a bearing on patient experience.

Facility timings, attitudes of reception staff and being able to access social grants often fell outside of the purview of TB providers and the treat regime, but from a patient perspective, were sometimes critical for their ability to adhere to treatment and overall assessments of the trustworthiness of the health system. Facility 2, with the largest patient load and TB/HIV burden, was also characterised by insufficient waiting areas, with patients often having to wait outside the facility and queueing early in the morning. As described in Chapter 5 and 6, contextual challenges of crime further challenged treatment access. Therefore, for many patients it was not enough for TB providers to be technically and interpersonally competent, but their willingness to accommodate these broader organisational obstacles (e.g. motivate for patients to receive social assistance or CCWs accommodating patients’ work and household constraints by visiting them at convenient hours), either reinforced or undermined trust. This was particularly the experience of the more acutely vulnerable patients, where challenges relating to the organisational context (e.g. access to disability grants, attitudes of reception staff, facility hours) and their ability to negotiate these successfully with providers, shaped their perceptions and experiences of providers as acting in their interests and providing fair and equal treatment. This, overall contributed to judgements of the trustworthiness of the institutions of care.

Vulnerability was also linked to patients feeling comfortable, welcomed and included within spaces in the health facility. The findings suggest that men and foreign nationals found health facilities challenging regarding inclusiveness. For several men, health facilities were perceived and experienced as female spaces, where women dominated the spaces both as patients and providers, which discouraged male participants from accessing care, and even when they did, it was uncomfortable due to hegemonic norms of masculinity (i.e. toughness and physical strength). This finding is consistent with other studies from South Africa (Orner *et al.*, 2008; Leichter *et al.*, 2011; Gittings, 2016) and internationally (Skovdal *et al.*, 2011), that care-giving is feminised. Women

access healthcare not only in relation to their own health, but also for their children. Societal institutions which establish women as care-givers, discouraging if not excluding men from care-giving roles, contributes to the relative absence of men in health facilities, both as seekers of care on behalf of their families and as healthcare providers. Moreover, the absence of male providers was challenging for several male participants, where deeply ingrained gender norms necessitated gender concordance. Here again, providers' acknowledgment and willingness to accommodate gender norms around masculinity, through adapting organisational structures and institutional norms (e.g. male patients permitted to take their TB medication in a group) strengthened trust in providers. As Skirbekk *et al.* (2011, p. 1189) conclude, in a study of patient-physician relationships in Norway, 'A physician showing reciprocal humanity creates common ground with the patient'. In contrast, the poor experience of foreign nationals in accessing healthcare (specifically in Facility 3), illustrates how their experiences were the outcome of poor organisational support structures (e.g. absence of interpreters, signs in foreign languages) and discriminatory attitudes of providers. Crush and Tawodzera (2014) describe this as medical xenophobia, which in the most extreme case, contributes to a denial of care. Once again, the experience of vulnerable groups (i.e. male and foreign nationals) illustrate the notion of the health system as a social institution (Gilson, 2003; Freedman, 2005), which often patterns broader societal norms and discrimination based on gender, class and rights in relation to citizenship.

Giddens (1990, p. 85) argues that 'although everyone is aware that the real repository of trust is in the abstract system, rather than the individuals who in specific contexts "represent" it. However, in this study, organisational challenges were often not associated with and attributed to the health facility as an organising system. Rather, in most instances, patients perceived healthcare providers as having the discretionary power to adapt organisational arrangements in ways that accommodated their needs. This was similar to previous research (Ward and Coates, 2006; Piippo and Aaltonen, 2008; National Sample Survey Office, 2015), where organisational challenges were blamed on front-line healthcare providers since they, as Giddens (1991, p. 85) describes were the 'flesh-and-blood representatives' or access points of the health services. This further suggests that patient interactions with healthcare providers build interpersonal-trust and this in turn support and sustain "faceless" or institutional trust. While this study has demonstrated that providers in many instances exercised their discretion in adapting policies to accommodate patients, their agency and overall ability to cultivate and meet patients' expectations of trustworthiness was often constrained by the broader TB policy framework, organisational arrangements and their professional status (clinical versus non-clinical). This in turn had consequences for providers' own expectations of patients,

management and their employing organisation. The related findings from this study are explored in relation to the literature in the next section.

***Question 3: What patient-related and institutional-related factors build provider trust in patients?***

To restate, in this study, provider trust is understood as the confidence (or positive expectation) that the patient and the organisational context in which health services are delivered, enables the provider to offer appropriate care for the patient, in a way that allows the provider to fulfil his professional responsibilities and is not harmful for him/her either personally or professionally. Provider trust in patients was shaped by perceptions and experiences of patients' trustworthiness; and institutional factors which had a bearing on provider's experiences. It was constructed and maintained *viz-a-viz* patients and the employing organisation, when provider expectations and goals were met. Expectations related directly to providers' needs, explicit or implied, and expected obligations of both patients and the employing organisations. This had consequences for perceptions of risks and assessments over trustworthiness of the patients and managers in the relationships. Each of these will be discussed in more detail below, reflecting on the broader literature.

***Trusting the patient***

As Rowe and Calnan (2006, p.379) argue, 'Power is fundamental to trust relations wherein one party is dependent on the other; without such vulnerability trust would not be necessary'. Findings from this study confirm that in the relationship between patients and providers, trust is as relevant for providers as it is for patients. The implications of providers' vulnerability for the distribution of power in the patient-provider relationship is seldom acknowledged and explored in detail in the literature. Although providers are recognised as the more powerful in the relationship, given their technical expertise and the patient's vulnerability regarding illness and uncertainty, this study has revealed that providers are also vulnerable, given that they also have expectations of and are dependent on patients. When provider vulnerability was recognised and responded to in a manner that met their expectations and consequently they felt safe, trust emerged and was maintained.

What were the needs and expected obligations that providers articulated in relation to patients? These obligations related primarily to treatment adherence and various aspects of interpersonal communication, of which respectful engagement and recognition were critical. When patients demonstrated personal commitment, and adhered to treatment as well as respecting professional boundaries, providers were more willing, for example, to trust and permit their patients to take their treatment unsupervised. Therefore, trust 'is an attitude that allows for risk-taking decisions' (Luhmann, 1988, p. 103).

The ability of patients to adhere to treatment was an important measure of performance (assessed by cure rates and percentage defaulting, as described in Chapter 5 on context), by which both patients and the whole cadre of TB providers (i.e. CCWs, DOTS supporters, professional nurses, adherence counsellors) were judged. Treatment adherence becomes all the more critical in a policy context where providers' performance is based on an achievement of institutionally entrenched, quantitative targets, which they argued were overly ambitious and unachievable. As Erasmus and Gilson (2008, p. 363) reflect, 'The ways in which policies are framed by and for implementers can be another often overlooked exercise of power that influences outcomes ...'. In this study, the outcome of the policy focus was to compel providers often to focus narrowly on and prioritise treatment adherence, ritualised through the policy of DOTS and task-oriented care (Lewin and Green, 2009), to the detriment of a more patient-centred approach (van der Walt and Swartz, 2002). As Lewin and Green (2009, p. 1467) argue, the current practice of DOTS, '... reproduces relations of power between patients and providers: first, through the medicalisation of the illness to create a sustainable "sick role", and second, through constructing the patient as a passive, non-trustworthy recipient of care in need of monitoring and control'. Not only did this conflict with but also undermined the realisation of a more patient-centred approach, which at its centre, prioritises relationship building through time spent and active participation of the patient in decision-making, which are necessary for the recognition of the deeper structural factors (i.e. socio-economic status, gender, access to social networks) contributing to poor treatment adherence. The focus on performance indicators reduces patients from people to targets, and in combination with DOTS, encourages the practices of negative labelling of patients (i.e. defaulters, chronic defaulters, missing link, drifter, *stoute klong*; refer to Chapter 7 on provider trust) by providers. This, as Lewin and Green argue (2009, p. 1468), '... juxtaposes professional authority with patient disempowerment, constructing and maintaining the micro-level power relations within the provider– patient interaction in which patients are subordinated and in which the patient's body is the centre of both control and resistance'.

As evident from this study and others, located in high-burden TB/HIV facilities and economically marginalised communities, where many if not most patients were acutely vulnerable, treatment adherence (or defaulting as referred to providers) was a wide-spread challenge, severely undermining the ability of healthcare providers to achieve their targets. This not only challenged patient-provider relationships, but also limited the construction of patient trustworthiness judged by treatment adherence, which itself has been widely acknowledged to often lie outside of a patient's control and often a consequence of underlying socio-economic and historical structural determinants. As Erasmus and Gilson (2008, p. 362-363) observed 'Implementers may exercise

power in pursuit of their own interests, but also, or as well, in reaction to the challenges of their working environments, or central actors' efforts to control them, or in adapting policy interventions better to address their own understandings of local need ... Such adaptation is particularly important in health care, given the need to respond to varying patient circumstances'. Similarly, in this study, when providers were able to adapt the policy to suit patients' specific needs (e.g. self-supervision of treatment to assist patients in incurring travel costs, administering DOTS to patients in groups), this not only encouraged treatment motivation, but also established mutual trust. As evident from this study, adaptation which enables treatment access and adherence is possible when providers believe they have the discretionary power within the ambits of the policy. As evident from this study, explicit granting of discretionary power by management was not evident, and providers often exercised their discretion 'in the moment' of responding to patient needs.

Providers' willingness to adapt policy to accommodate patient needs was triggered not only by patient trustworthiness based on treatment adherence, but also consideration and judgements of patients' emotional competencies (i.e. willingness to take responsibility for health) and interpersonal behaviours and attitudes (i.e. integrity, recognition, respect) within the patient-provider relationship. The study reveals that experiences of patient trustworthiness based on interpersonal dimensions was not uniformly distributed, but rather patterned on professional hierarchies, which conferred respect and maintenance of professional boundaries. For example, doctors, and specifically female doctors, indicated that patients were respectful of patient-provider boundaries, which they credited to their professional status as doctors in the relationship. This suggests that professional status over-rode gender norms in protecting them from sexual harassment. In contrast, CCWs often spoke of the vulnerability of working in unsafe communities, and this experience was deeply gendered. With respect to female CCWs, entering the personal spaces of particularly male patients carried the very real risk of physical and sexual harassment. For the few male CCWs, while gender norms and their maleness was an asset for building relationships with male patients, their personal safety was ironically, in some communities, at higher risk and not necessarily a protective factor. Finally, CCWs in Facility 2 were unhappy that MDT meetings were held outside of their work hours which conflicted with child-care demands. However, they accepted this arrangement and did not raise this issue with their supervisors or management within the health facility. While challenges of treatment adherence, disrespect and personal safety manifested in the patient-provider relationship, the ability of providers to negotiate these challenges was directly linked to and constrained by policy, institutional arrangements and management practices in the workplace.



### *Trusting management and the employing organisation*

This study has also confirmed that TB providers across the professional hierarchy articulated the need to trust their employing organisation and its representatives (i.e. namely managers and supervisors) to provide a supportive and enabling environment, in order that their professional experiences met their expectations. As Simpson (2007) argues, trust comprises the self, the specific partner, and a specific goal in a specific situation. What were the expectations of TB healthcare providers with respect to the workplace and management? Consistent with the literature (Manzi *et al.*, 2004; Greenspan *et al.*, 2013; Topp *et al.*, 2015) their expectations were a combination of financial (i.e. remuneration, secure employment) and non-financial (i.e. recognition and respect from management, opportunities for professional growth, supportive relationships with co-workers and enabling working conditions including physical safety).

Perceptions and experiences of risk were directly related to perceptions and experiences of vulnerability. Similar to the vulnerability experienced in relation to patients, the more vulnerable providers felt with respect to management and the employing organisation, the larger the perceived risk for trust being exploited or abused. A significant finding of this study was that the sources and magnitude of providers' vulnerability was directly linked to their professional background, socio-economic status, gender and employer, i.e. distribution of power was not evenly distributed among TB healthcare providers. As Pilgrim *et al.* (2010, p. 3) observe, '... trust does not stand alone, but is part of a wider discussion about uncertainty in our lives'. Providers articulating the most uncertainty and vulnerability in their lives were those lowest in the professional hierarchy (i.e. CCWs, TB assistants and DOTS supporters). This vulnerability arose from a complex interplay of factors relating to the provider (i.e. lack of professional status and poor socio-economic class, gendered roles embedded in patriarchal systems) and the workplace (i.e. unsafe working conditions, poor recognition by management, poor remuneration, experiences of feeling excluded from the organisational culture). These providers were also the most socio-economically vulnerable, often working in the same economically marginalised communities in which they lived. In contrast, providers located higher in the professional hierarchy (i.e. doctors and professional nurses), who worked primarily in the comparatively safer spaces of the health facility, expressed relatively less professional and personal vulnerability in relation to both patients and the employing organisations. Interaction of provider vulnerability with experience of work-place factors shape providers' overall experience, with implications for trust in their managers and workplace. More vulnerable providers (e.g. CCWs) had higher expectations of workplace-related factors and overall poorer experiences of health system institutions, where many of their expectations were not met, contributing to lower levels of institutional trust.

This study has demonstrated that while provider trust in their supervisors and employing organisation was a complex outcome of their material and non-materials expectations being met, managerial action and leadership was often the fulcrum which tipped the balance in favour of building or undermining trust. Mullarkey *et al.* (2011, p. 90) argue, specifically in the context of critical care nursing, but which has broader relevance for the healthcare system, '... there is a greater need than ever to develop trustworthiness between staff and nursing managers to promote teamwork, improve communication ... Team trust is required, particularly in critical situations, to enhance the quality of patient care, to promote a caring and supportive clinical environment and to engender effective team work'.

Management and leadership practices which demonstrate a commitment to inclusion, relationship building, communication engendering cohesion and team-work in an organization are particularly important in the context of TB/HIV integration. This study has demonstrated in equally high-burden, resource-constrained facilities, contrasting management practices can have very different implications for staff trust, morale, cohesion, organisational commitment and motivation. Health facility managers (e.g. Facility 3) which encouraged an organisational culture which valued staff relationships, feedback, recognition and reward, and conveyed a culture of care through inclusive practices, built cohesion and trust in providers. In contrast, in Facility 1, leadership practices which was experienced as critical, unsupportive and focused narrowly on performance indicators, conveyed the message of a blame-culture, where staff commitment to patient was not recognised and valued, contributing to an undermining of trust in management, with implications for low staff morale, demotivation, low organisational commitment and staff turnover.

In addition, positive and supportive managerial practices, even in a facility such as Facility 3, were not equally experienced by all providers. Receipt of supportive management practices was dependent on professional status and whether one was employed by the department of health or NGO. NGO staff across all three facilities reported and were observed being excluded from organisational practices and rituals (e.g. exclusion from end of the year parties in Facility 2), recognition and rewards (e.g. formal awards by the department of health for contributing to facility performance in Facilities 1 and 3), and access to facility resources (e.g. exclusion from sharing facility resources such as tea/coffee in Facility 3). This contributed to an overall sense of alienation from the formal, hierarchical healthcare system, amplified by equally alienating, often invisible and unsupportive management practices from the NGO. Within the broader national and global policy initiatives calling for shifts away from vertical programmes towards integrated services (e.g. TB/HIV integration), where services will increasingly be delivered through inter-professional teams, cohesion and successful integration of all team members is essential for effective service delivery.

As observed in this study, an alienating environment can significantly impact on an individual's sense of belonging in an organization, contributing to low staff morale and retention challenges.

Moreover, as described earlier, many of these providers articulated a tension between their commitment to patient care and policy dictates focusing on targets. This is similar to research from South Africa and elsewhere. In South Africa, lay HIV-counsellors reported, 'What I've noticed what they [management] need is the stats' (Rohleder and Swartz, 2005, p. 397). In India, front-line providers in a community-based programme complained of management focusing on cure rates instead of patient care (Singh *et al.*, 2002). In such contexts, providers particularly CCWs and DOTS supporters who felt alienated, coped and filled the gaps through creating their own rituals and practices engendering team work and support (i.e. visiting patients together if the patient was challenging, social get togethers etc.)

This study has also confirmed that, despite unsupportive management practices and often poor working conditions, providers generally articulated the importance of their work and being motivated by a higher, spiritual calling ("instrument of God") and a desire to improve the health and well-being of "our people" (see Chapter 7). Topp *et al.* (2015, p. 1 of 14) refer to these as 'higher order social aspirations'. However, these altruistic motivations for care were often in tension with the lived reality of poverty and financial need driving entry into care work, particularly on the part of non-clinical, volunteer staff (i.e. adherence counsellors, CCWs, TB assistants). This supports findings from a growing body of research examining the experiences of particularly CCWs in both South Africa (Daniels *et al.*, 2012; Colvin and Swartz, 2015; Swartz and Colvin, 2015) and internationally (Mumtaz *et al.*, 2003, 2013; Zulu *et al.*, 2014; Daniels *et al.*, 2015; Topp *et al.*, 2015; Kok *et al.*, 2016). As Topp *et al.* (2015, p. 2 of 14) argue '... that rather than being a strict matter of individual choice, volunteers [CCWs] may be entering and remaining in service because they lack alternative livelihood options'. Gould-Williams (2003, p. 35) argues that management and human resource practices 'send powerful signals to employees about the extent to which the organization trusts them' and 'if organizations fail to deliver on contractual or other promises, employees' sense of indebtedness or mutual obligations will be reduced. This may arise if, for example, organizations do not deliver on individual career development programmes or promised working conditions'. Schneider *et al.* (2008, p. 184) cogently summarise the status of CCWs as '... an undervalued, flexible and exploited labour force without normal rights or benefits such as leave, maternity benefits and pensions'. This status not only increased the risk of exploitation in the relationship between very vulnerable CCWs and the employing organisation but also contributed to a lived experience of what Mumtaz (2003, p. 261) described when documenting the experience of CCWs in Pakistan as '... far from enjoyable and

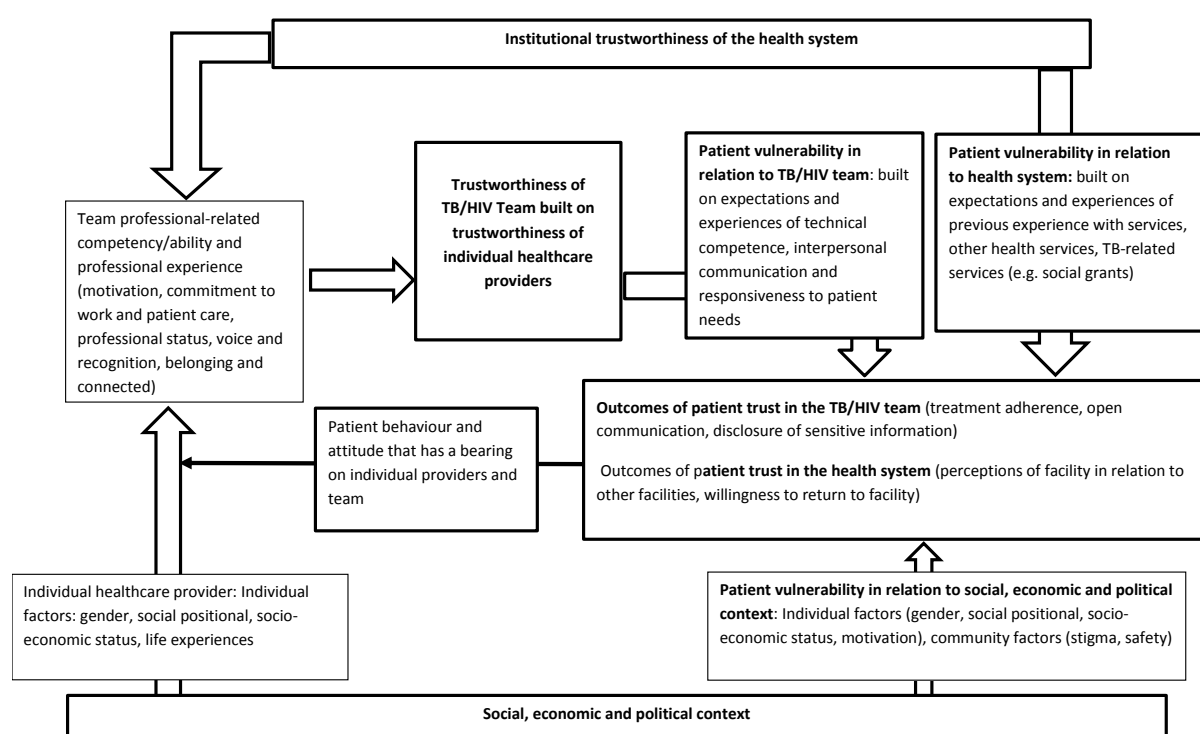
fulfilling’. As Greener (2003) argues, under such circumstances, the acutely vulnerable (i.e. CCWs) are in a relationship of ‘enforced dependency’, where trust is not voluntary but forced because of the lack of alternatives.

## Part 2: Reflecting on the overall research question

This section concludes the discussion by responding to the overarching research question (i.e. How is trust built and experienced between patients and healthcare providers for TB treatment in primary care settings and how does gender influence those relationships?). The question is addressed by examining the ways in which the study contributes to extending conceptual understanding of trust, gender and TB (see Figures 9.1. and 9.2), building on the original conceptual framework (Chapter 3). This study has extended the original conceptual framework to highlight the centrality of vulnerability and trustworthiness (on the part of patients and providers) within the patient-provider relationship for TB treatment in low-resource, high-disease burden settings.

Figure 9.1 presents the influences over and outcomes of patient trust in providers and the health system, which offers pointers to the pathways for building trust (as discussed in Chapter 6). Patient vulnerability and expectations are critical dimensions of patient trust in providers and the health system. Vulnerability is the outcome of the social, economic and political context; judgements over trustworthiness of the TB/HIV team; and judgement over the trustworthiness of the health system which operate simultaneously, and if not addressed, result in perceptions of provider and institutional untrustworthiness.

Figure 9.1: How is patient trust built in healthcare providers and the health system?



At the social, economic and political context level, gender is an important dimension of patient vulnerability, intersecting with other social stratifications at the individual (e.g. socio-economic status, employment status etc.) and community level (i.e. stigma, access to social networks of support) to shape patient roles, norms and access to resources, contributing to differences in experiences of the foundations of trust for male and female patients. In relation to providers and ultimately the TB/HIV team, judgements of trustworthiness are built around patient vulnerability and related expectations of technical competency, interpersonal communication and responsiveness to both illness and psycho-social needs. In relation to the health system as an institution, trustworthiness is built on expectations that extend beyond the illness to include experiences with other services, previous experiences and psycho-social needs.

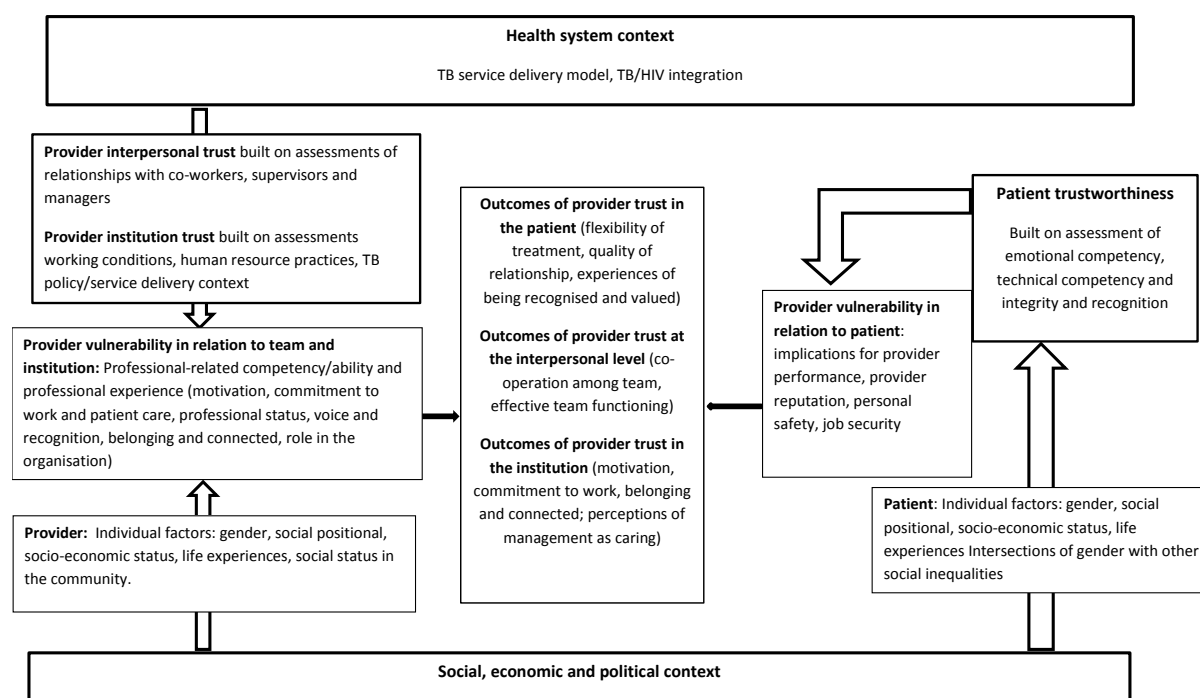
Much of the literature has focused on patient trust in a single provider and either doctors or nurses. However, with respect to the treatment of TB and TB/HIV in primary care settings, patients engage with a team of multiple providers, comprising clinical and non-clinical providers in both the facility and community. Therefore, while trust is often built around interactions and relationships with *individual* providers, this contributes to judgements over trustworthiness of the *team*. Outcomes of patient trust in providers and the health system enable treatment adherence, but also have implications for the willingness to return to the facility, and quality of relationships with providers. Finally, outcomes of patient trust in providers, demonstrated through behaviours and attitudes (e.g. respect, willingness to disclose information, treatment adherence etc.), may themselves have a bearing on the experiences of the TB/HIV team. The professional experiences of the TB/HIV team are also built around judgements over the institutional trustworthiness of the health system. This is presented in more detail in Figure 9.2.

Turning to providers, trust in patients and managers is under-studied, arguably because of the focus on and well-founded evidence about the inherent vulnerability of the patient (described earlier in the literature review). However, as this study has demonstrated, the importance and relevance of provider vulnerability operating at the individual level and within healthcare teams, in relation to patients and managers has implications for provider trust in both patients and managers. This requires extending our conceptual understanding of patient-provider trust to encompass the influence of institutions and patients on healthcare providers, and providers' judgements about trust (See Figure 9.2).

Within teams, vulnerability in relation to patients and team members is influenced by individual factors (i.e. professional status, gender, socio-economic status etc.) and location of work, and ways in which managerial practices can potentially mitigate related challenges. Broader policy changes

which required, in this context, a shift to integration of TB and HIV services, and shifting from facility-based DOTS and monitoring of treatment towards shared-decision-making and patient self-supervision, entails a shift in the balance of power between patients and providers. This has implications for providers' vulnerability and related expectations of both patients and managers.

**Figure 9.2: How is provider trust built in patients and the health system?**



With respect to provider trust in patients, judgements of patient trustworthiness are based on assessments of competency, integrity and recognition, resulting in outcomes which have a bearing on the flexibility of the treatment process, quality of the patient-provider relationship and the experience of the provider. Similarly, judgements over trustworthiness of managers built around interpersonal (e.g. appreciation, respect) and institutional (e.g. salaries, safety, security) trust have implications for outcomes at the provider level, including team functioning, motivation and organisational commitment.

In summary, trust is a complex phenomenon, dynamic, constantly being tested, affirmed and re-affirmed, through multiple engagements on the part of both providers and patients. Trust is both a process and an outcome (Johns, 1996) and is context-specific and sensitive. For both patients and providers, trust is built and sustained through a complex range of interpersonal and institutional factors, shaped at the level of the individual, community and health-system. Trust is about interdependence between patients and providers. The interdependence and vulnerability of both in the relationship is not always recognised and understood regarding its implications for mutual trust.

Mutual trust is nurtured in contexts where both patients and providers feels safe to be vulnerable, and as Østergaard (2015) argued, without eliminating the inherent power differences.

## **Chapter 9: Conclusion**

This chapter comprises three sections. The first section situates the findings in relevant, current national, provincial and global health policy reforms. The second section addresses research sub-question 4 (i.e. what are the implications of study findings for management and organizational reforms and practices, and how might these strengthen gender aspects of patient-provider trust relationships for TB treatment). The third and final section reflects on the research learnings from the study.

### **National and global health policy context of TB and TB/HIV services (2017)**

Chapter 5 highlighted several of the key national health policies which have been important for influencing the features of the current TB programme and its integration with HIV services. In 2011, at the beginning of this study, the most significant and relevant was the *National Strategic Plan (NSP) on HIV, STIs and TB 2012-2016* (South African National AIDS Council, 2011), which called for the integration of TB and HIV services to tackle the co-epidemic more coherently. The follow-up *NSP on HIV, STIs and TB 2017-2022* (South African National AIDS Council, 2017) is currently in draft, waiting finalisation following public review and comment. The key feature of the current NSP is a call to accelerate progress in reducing the morbidity and mortality associated with HIV, TB and STIs, through several strategies. Of relevance for this study are the recommendations for expanding coverage of services, the strategic framework for multi-sector partnership to address the social and structural drivers of HIV, STIs and TB, and improved access to psycho-social support.

Notwithstanding these important developments, specifically for improving diagnosis and treatment among people living with TB and/or HIV, the phased roll-out of South Africa's National Health Insurance (NHI) scheme promises far-reaching health reforms for the overall health system (National Department of Health, 2015), including and beyond TB and HIV. The NHI is a key strategy for achieving universal health coverage (UHC), which holds the promise of equitable, efficient and quality health services, accessible to all South African residents, irrespective of their ability to pay. Minister of Health, Dr Aaron Motsoaledi described 'primary health care [PHC] as the heart-beat of the NHI' (Fokazi, 2013), with PHC requiring a more integrative horizontal (versus disease-specific) approach with reorientation towards preventive and promotive services. This will be realised through the strengthening of district health systems and the implementation of Ward-Based Primary Health Care Outreach Teams (W-BOTS) for improving community access to health care. The outreach



teams are nurse-led, comprising primarily CHWs and other health cadres (i.e. environmental health officers, health promoters). The focus is on preventative and promotive care, adherence and psychosocial support, with an overall focus on maternal and child health, HIV, TB and chronic non-communicable diseases (National Department of Health, 2011a).

There is also recognition of the fundamental role of healthcare workers, outlined in the *South African national strategic plan on HIV, TB and STIs 2017-2022* (South African National AIDS Council, 2017, p. 103), 'Only a robust, resilient system of human resources – one that prepares every worker to serve in a caring, people-centred and competent manner – will ensure that human resources are sufficient and that all actors are working in harmony to achieve the goals and objectives of the NSP.' Equally relevant, is the recommendation for CHWs, as a critical component of the Ward-Based Primary Health Care Teams (W-BOTS), calling for their integration into the health system, requiring formalisation as a cadre, appropriately trained and supported (South African National AIDS Council, 2017). Similarly, the *National Human Resources for Health Strategy for the Health Sector: 2012/13 – 2016/17* calls for '[d]evelop[ing] the training infrastructure, plans, reimbursement and career pathways for Community Health Workers' (Matsoso and Strachan, 2011, p. 55), requiring agreement on a standardised scope of work, competencies, training and supervision package and conditions of service.

The findings of this study also have relevance in the context of several important global policies and strategies. These include the succession of the United Nations Millennium Development Goals (MDGs) with Sustainable Development Goals (SDGs) and specifically Goal 3<sup>29</sup>(United Nations General Assembly, 2015), the adoption of the World Health Assembly of the *Framework on Integrated People-Centred Health Services* (IPCHS) (WHO, 2016b), the *World Health Organisation (WHO) End TB Strategy* (WHO, 2015b) and the *WHO Global Strategy on Human Resources for Health: Workforce 2030* (WHO, 2016c). The key features of these policies and frameworks are described in Box 9.1.

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<sup>29</sup> United Nations Sustainable Development Goals (SDGs) and specifically Goal 3, articulated as "Ensuring healthy lives and promoting well-being through the achievement of universal health coverage"(United Nations, 2015, p. 16).

### Box 9.1: Key international health systems policies and strategies

- **UN SDG 3:** Ensure healthy lives and promote well-being for all at all ages and Target 3.3 calls for “By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases” (United Nations, 2015, p. 16)
- **Framework on Integrated People-Centred Health Services:** articulating a universal vision for improved healthcare access to services that are acceptable (i.e. safe, effective, timely, affordable, and quality), emphasising community and individual needs, underpinned by values of respect encompassing all people in the health system. The five interdependent strategies are: (1) empowering and engaging people and communities; (2) strengthening governance and accountability; (3) reorienting the model of care; (4) coordinating services within and across sectors; and (5) creating an enabling environment. (WHO, 2016b, p. 4)
- **WHO End TB Strategy:** Aims to end the global TB epidemic, with targets to reduce TB deaths by 95% and to cut new cases by 90% between 2015 and 2035, and to ensure that no family is burdened with catastrophic expenses due to TB. Strategy focuses on three pillars and sub-components; 1) integrated, patient-centred care and prevention; 2) bold policies and supportive systems; and intensified research and innovation. Alignment between WHO's End TB Strategy and SDGs with respect to indicators and targets. (WHO, 2015c, p. 4)
- **Global Strategy on Human Resources for Health: Workforce 2030.** To improve health, social and economic development outcomes by ensuring universal availability, accessibility, acceptability, coverage and quality of the health workforce through adequate investments to strengthen health systems, and the implementation of effective policies at national, regional and global levels. The specific objectives are to 1) optimize the existing workforce in pursuit of the SDGs and UHC, 2) anticipate future workforce requirements by 2030, 3) strengthen individual and institutional capacity to manage HRH policy, planning and implementation and 4) strengthen the data, evidence and knowledge for cost-effective policy decisions. (WHO, 2016c, p. 8)

There are several points of alignment across the national and the global policies and strategies for tackling TB and TB/HIV, and strengthening the health system more generally including:

- Recognition and targeting of services for vulnerable and marginalised groups. The NSP identifies them as ‘... low literacy, residents of informal settlements, migrants, women, people who are poor, miners and people living in peri-mining communities, inmates in correctional facilities, and the contacts of people with TB’ (South African National AIDS Council, 2017, p. 52). Similarly, the Framework on IPCHS also recognised vulnerability and marginalisation linked to health care access arising from ‘factors that include income, education, residence, gender, ethnicity, working conditions or migrant status’ (WHO, 2016b, p. 6).
- Recommendation for multi-sectoral action, tackling the underlying social and economic determinants of TB (e.g. poverty reduction, housing, food and nutrition, education) (WHO, 2015b; South African National AIDS Council, 2017).
- Recommendation for diverse inter-professional healthcare outreach teams (i.e. nurses, community care workers etc.) at the primary health care level as critical for improving healthcare access to preventive, promotive and curative and chronic services (e.g. TB, HIV, diabetes, hypertension) (Matsoso and Strachan, 2011; WHO, 2016c).
- Recognition that CHWs are a critical component of an outreach team for achieving the objectives of all national and global health and TB policies and strategies (WHO, 2015b; South African National AIDS Council, 2017).

- Horizontal integration of services. For instance, the WHO End TB Strategy calls for improved integration of TB services with HIV as well as other services (maternal and child health, nutritional care, diabetes care, lung health, and mental health services) (WHO, 2015b).

While these points of alignment between national and global policies are encouraging actions for streamlining resource allocation, and more coherently developing national and sub-national programmes, there are areas that have received insufficient attention. These include people-centred health systems and health systems as social institutions of trust.

The Framework on IPCHS (WHO, 2016b, p. 2) defines people-centred care as:

an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, **trusted health systems** that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences. **People-centred care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment.** People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services. [emphasis added]

However, with the exception of the Western Cape provincial department of health (Western Cape Department of Health, 2014), national (National Department of Health, 2015; South African National AIDS Council, 2017), and global (WHO, 2015b) strategies remain focused on *patient-centred*, not *people*:

The vision for 2030 is: Access to person-centred, quality care ... multiple perspectives of this vision...

include those of patients, staff, the community, the Department [of Health], spheres of the government and strategic partners ... A person-centred approach, built on a relationship of trust, leads to increased compliance, improved quality of care and, ultimately, better health outcomes. (Western Cape Department of Health, 2014, p. x, 24)

'The implementation of the Patients' Rights Charter will be strengthened to ensure a patient-centred approach where the principles of patient's rights, choice, empowerment, participation and access to safe quality and appropriate services and information are recognised' (National Department of Health, 2015: 41)

Integrated, patient-Centred Care and prevention puts patients at the heart of service delivery through focus on early diagnosis, treatment, TB/HIV and comorbidities and preventive treatment. (WHO, 2015b)

While the focus on patients is justifiable and necessary, a shift towards *people-centred* care is wider and more inclusive, through recognising patients more holistically regarding health and well-being and not only illness. However, equally important from the perspective of this study is that a people-

centred approach also recognises healthcare providers beyond an instrumental role as resources in the system, but as people, with values, needs and vulnerability. The tendency in all the policies and strategies (national and global) is to take a very reductionist, quantifiable and measurable approach to healthcare providers. This applies also to the *Global Strategy on Human Resources for Health: Workforce 2030* (WHO, 2016c), where descriptive language relating to healthcare providers is limited to 'investment', 'optimize', 'capacity', 'data' and 'cost-effective'. Recognising healthcare providers' humanity and vulnerability demands a different language which gives effect to and is informed by a recognition that places them - especially those operating at the coalface of service delivery - at the heart of the health system, alongside patients:

'When we see systems as social institutions primarily defined by the people who constitute them and their human relationships, the ways of bringing about change in health systems go beyond altering written rules and distributing resources, and extend to managing these chains of relationships effectively'. (Sheikh *et al.*, 2014, p. ii3)

The second omission is the related issue of trust. As Sheikh *et al.* (2014, p. ii2) argue, '... mutual trust, dialogue and reciprocity, and their effectiveness correlates to the quality of these human relationships'. The findings from this study strengthen the evidence base of the centrality of trust for both patients and providers, for conditions such as TB and HIV, and the health system more widely. However, this recognition and appreciation of the value of trust is absent in all documents but the Framework on IPCHS (WHO, 2016b).

In the South African context, while the vision espoused under NHI is transformative, even revolutionary, built on principles of equity, social justice and solidarity, its implementation and ultimate achievements are likely to be dogged by challenges of trust in the health system (Weimann and Stuttford, 2014; Rispel *et al.*, 2016; The Guardian, 2017) as well as other health-related sectors (e.g. Department of Social Development). Trust in public social and development institutions has been further challenged by recent scandals of corruption and maladministration. The South African Social Security Agency (Sassa) which is located within the Department of Social Development works closely with the Department of Health in ensuring access to the disability grant for people with HIV and TB. The current crisis within Sassa, threatens the non-delivery of social grants (including the disability grant) to millions of vulnerable beneficiaries including patients with TB and HIV (Corruption Watch, 2017). This has implications for patient perceptions of quality of care and fairness in treatment access, based on broader social and development support linked to key public institutions.

In the following section, policy and interventions that directly address both patient and provider vulnerabilities, rooted in the personal, community and health facility environment, will be considered as levers for enhancing patient (provider) trust in providers (patients) and the health system as a social institution.

## **Implications of study findings for management and organisational reforms and practices**

In this section, specific strategies for building patient and provider trust in the other and the health system are proposed, informed by the findings and the revised conceptual framework (Chapter 8), and are anchored in the specific policies and strategies within the relevant national and global policy reforms described above. While many of the recommendations are specific to the TB and TB/HIV model of care, they are significant for building trust and enhancing the responsiveness of the health system more broadly.

In summary, the recommendations identify a number of institutional and organisational actions which are necessary for facilitating the building of trust on the part of patients and healthcare providers in the context of TB and the health system more widely. At the same time, it is important to recognise that their implementation will not automatically build trust, but their presence will make it easier for trust to develop.

### ***Recommendations for building patient trust in healthcare providers and the health system***

The following recommendations are made:

- Improving TB treatment access and adherence through inter-sectoral action and partnerships
- Enabling and promoting gender-sensitive TB and TB/HIV services
- Improved psycho-social support for TB and TB-HIV co-infected patients
- Enabling and promoting migrants' access to TB services
- Rewarding patients for adherence and treatment completion.

#### ***Improving TB treatment access and adherence through inter-sectoral action and partnerships***

This study has confirmed that in contexts characterised by poverty, unemployment and social challenges, treatment access and adherence is the outcome of a complex intersections of factors operating at the personal (e.g. socio-economic status, gender, HIV co-infection, social support etc.), wider community (e.g. stigma etc.) and health service level (e.g. accessibility of treatment, relationships with providers etc.). These findings that the burden of TB and the TB/HIV epidemic

disproportionality burden the poorest and most vulnerable are confirmed in the wider literature from South Africa and globally (Noyes *et al.*, 2007; Kagee and Martin, 2010; Fried *et al.*, 2015) and are reflected in the revised conceptual framework (Figure 9.1, p. 173).

This calls for intersectoral co-ordination and partnerships (i.e. social protection and poverty alleviation), as critical for addressing the social determinants of TB (WHO, 2015b, 2016b; South African National AIDS Council, 2017). The successful implementation of these inter-sectoral partnerships (i.e. between Departments of Health and Social Development in South Africa) are important for building strong social support systems and safety nets, which in turn contribute to strengthening institutional trust, treatment access and adherence, as borne out in this study. The success of these initiatives will depend on the Departments of Health and Social Development working closely and effectively together.

However, as this study and previous studies (Woolgar and Mayers, 2014; Govender *et al.*, 2015) have shown, the weak inter-sectoral co-ordination between the two departments has contributed to ambiguity in, for example, eligibility guidelines for the disability grant, leading to patients believing that they are being unfairly denied access. This ultimately challenges patient-provider relationships, mutual trust and treatment adherence. In addressing these challenges, the following recommendations are made, specifically with respect to inter-sectoral co-ordination between the Departments of Health and Social Development in South Africa:

- Assessments for eligibility for the disability grant should be broadened to include assessments by a social worker (not only a medical doctor) to take account of social circumstances in addition to clinical guidelines (Woolgar and Mayers, 2014).
- Assessments of patient eligibility need to be more gender-sensitive and responsive, recognising that social circumstances (e.g. poverty, unemployment and access to social support) are inextricably linked with gender (i.e. roles, norms and access to resources).
- Eligibility for social grants needs to be supported by patient and public information initiatives, which explain the process and eligibility criteria in clear and unambiguous language. This can potentially reduce opportunities for misunderstandings between patients and providers, by locating the provider's decision within a broader context of institutional trustworthiness.

#### ***Enabling and promoting gender-sensitive TB and TB/HIV services***

This study has confirmed the role of gender as an important source of vulnerability for both men and women. Gender manifested in access to resources (e.g. access to social support, employment), social

roles (e.g. household head, child-care) and social norms (e.g. availability of male and female healthcare providers).

The Framework on IPCHS calls for the reorientation of the model of care to incorporate gender and cultural preferences in the design and operation of health services (WHO, 2016b). The WHO *End TB Strategy* (WHO, 2015b) and the NSP 2017-2022 (South African National AIDS Council, 2017) acknowledge gender, but with a restricted view, with the former and latter referring to gender as it relates to extending coverage to social protection and gender-based violence, respectively. A more inclusive view of gender - acknowledging and responsive to the influence of contextual factors in shaping roles, norms and access to resources (Muralidharan *et al.*, 2015; Morgan *et al.*, 2016) - is required if the TB targets for improving diagnosis, treatment access and adherence are to be met. Specific entry points for promoting gender-sensitive services include for example the organisational aspects of TB and TB/HV services, which challenge access and treatment for both men and women and recognising in all relevant policy documents, gender as a vulnerability.

Muralidharan *et al.* (2015) identify opportunities for integrating gender and gender-awareness into the health system and health services as operating along a continuum, from blind (i.e. ignores or reinforces gender dynamics), accommodating (i.e. works around but does not seek to change gender dynamics and inequalities), and transformative (i.e. seeks to change gender inequalities dynamics). Strategies for accommodating gender roles and improving access require adapting services (Nyirenda *et al.*, 2006). With respect to TB services, this includes for example the improved provision and delivery of outreach services which bring services closer to the patient and the community as recommended in national and global health reform policies (WHO, 2015b, 2016b; South African National AIDS Council, 2017). This also requires improved organisational aspects relating to primary care facilities:

- *Improved outreach services* which address the opportunity cost of women's time (i.e. domestic role in the home and income-generating) and men's time (i.e. income-generating) and for both men and men, transport and costs which are critical for improving treatment access.
- *Within primary care facilities*, opportunities for improved flexibility in operational hours and timing of services, taking account the gendered roles of patients (i.e. caregiving, employment), needs to be considered. Improved TB/HIV integration, which provides a one-stop shop for managing patients with dual infection, could potentially play an important role in reducing waiting time in facilities. Within facilities, opportunities for creating child-friendly

spaces (e.g. play areas) need to be considered to accommodate women with children.

Finally, where possible and in response to patient need, opportunities for gender-concordance between patients and providers should be supported, for improved acceptability of care and treatment adherence (McAlearney *et al.*, 2012).

The previous section has highlighted the importance of inter-sectional action and the gender aspects of access to social grants. Improved access to social grants and nutritional supplements often enable treatment access and adherence, because they respond to the gendered roles of patients. Grants are a life-line for the livelihoods of dependent families of both male and female patients.

The study has revealed specific ways in which gender norms discourage men from accessing and adhering to treatment. In order to address this, Barker *et al.* (2010) argue for gender-transformative interventions, which require more detailed understanding of how masculinity is a source of vulnerability in accessing healthcare. Specific strategies for improving men's access and treatment include for example, the provision of safe social spaces, peer-based groups and encouraging community leaders to publicly debate health-damaging masculinities (Barker *et al.*, 2010; Skovdal *et al.*, 2011). Similarly, for TB and HIV services, improved access to social grants and nutritional supplements, besides enabling treatment access and adherence, may also potentially contribute to more affirming constructions of masculinity. This, in combination with peer support groups (e.g. adherence clubs), has the potential for health systems to be mechanisms for broader societal transformation, and in this instance, harmful gender norms relating to masculinity.

The above recommendations suggest a relatively passive role for patients. The *Framework on IPCHS* (WHO, 2016b) provides for a more active role (i.e. empowering and engaging individuals and families) in policies and interventions, including shared clinical decision and knowledge of health system navigation. An additional example is to involve patients in the planning of services, with specific reference to ART services, but which are relevant also for TB and TB/HIV integrated services. 'Looking at creative ways to engage these groups and respond to their concerns will increase both the gender equity and accountability of ART service provision' (Nyirenda *et al.*, 2006, p. 78).

The above recommendations, which recognise and address gender-based barriers to care and treatment, are critical for improving treatment access and adherence, enriching the treatment and the psycho-social health outcomes for patients. Equally important, they are also powerful symbols of recognition and respect for the patient as a person. Moreover, in acknowledging their multiple roles



and responsibilities beyond the treatment, and demonstrating adaptability in accommodating patient need, these actions have the potential to enhance trust in the health system as a social institution of care.

#### *Improved psycho-social support for TB and TB-HIV co-infected patients*

Suggested by this study and supported by the growing evidence base in South Africa, there is a high prevalence of mental disorders among patients with TB, and even higher for those co-infected with HIV (Kagee and Martin, 2010; Peltzer *et al.*, 2012), with implications for treatment adherence.

In recognition of the importance of psycho-social support, NSP 2017-2022 (National Department of Health, 2017, p. 33) calls for the provision of both psycho-social and mental health support, and the scaling up and improving of access to social grants, food security and nutritional support for people living with HIV and TB in need in every district. The NSP 2017-2022 goes further in recommending in-service training for all healthcare providers (i.e. facility and community-based) in order that they are able to screen, provide interim support for patients, and refer to comprehensive psycho-social support and mental health services.

However, Schneider *et al.* (2016, p. 158) caution with respect to task-sharing and integration of mental health services within existing TB and TB/HIV integrated services: ‘ Indeed effective services, especially task-sharing models of services, require strong training, supervision and support structures to ensure high-quality services and retention of human resources’. In the absence of these additional layers of support, burn-out, poor performance and attrition of healthcare providers are likely outcomes. In the present study, the facility with a fully-integrated TB-HIV service also incorporated a part-time social worker into the TB/HIV programme, whose key roles included amongst others, providing supportive counselling, connecting patients and families to appropriate resources and networks of support in the community, and facilitating patient referrals to social support services. It is recommended that in primary health facilities located in socially-deprived districts, with a high TB/HIV and psycho-social burden, social workers be integrated into the TB/HIV team.

#### *Enabling and promoting migrants’ access to TB services*

This study has found that in several instances foreign nationals experienced poor access to health care, including absence of interpreters, lack of signage in foreign languages, and in some instances, discriminatory attitudes of providers. The challenges experienced by foreign nationals in the South

African health system, and specifically the issue of medical xenophobia, has been documented (Crush and Tawodzera, 2014).

In key national and global policy documents (WHO, 2016b; South African National AIDS Council, 2017), foreign nationals or migrants are recognised as an underserved, vulnerable and marginalised group, with poor access to access to health services. NSP 2017-2022 (South African National AIDS Council, 2017, p. 58) calls for “targeted, migrant-friendly IEC materials and SBCC (i.e. social and behaviour change communication), including social media and translations into common non-South African languages”. Findings from this study also support the call for specific interventions which improve acceptability of the health services (Gilson, 2007; McIntyre *et al.*, 2009) and enhance institutional trust. These include:

- Integration of interpreters into the health services,
- Introduction of cultural competence training (Copeland and Butler, 2007),
- Workshops for providers that challenge discriminatory practices of providers towards foreign nationals, and at the same time prepare and support them to provide care for patients from diverse cultures and other nationalities, and
- Integration of foreign nationals into the wider institutions supporting the facility through, for example, participation in clinic committees, which can contribute to countering medical xenophobia (Crush and Tawodzera, 2014).

#### ***Rewarding patients for adherence and treatment completion***

This study has shown that patients’, particularly those who are acutely vulnerable and face multiple challenges in adhering to treatment, experiences of being considered trustworthy was a powerful motivator and restored a sense of self-worth for many patients, suggesting the potential for the health system and healthcare providers to play a transformative role in the lives of patients beyond treatment of the disease. Recognition and validation are critical for self-development (Maslow, 1970) and it is recommended that formal recognition (e.g. award of a certificate or trophy) be awarded to patients on the completion of their treatment.

#### ***Recommendations for building healthcare provider trust in the health system and patients***

Building provider trust in the health system and patients, as in the context of TB and the health system more generally, requires several actions. Relevant calls for action contained in national and global policy documents are outlined in Box 9.2 below.

## Box 9.2: Aspects of national and global health policies on human resources for enhancing the working environment

- Department of Health *HRH Strategy for the Health Sector 2012/13 – 2016/17*. The mission and vision of the HRH Strategy are 'ensuring the health workforce has an optimal working environment and rewarding careers' (Matsoso and Strachan, 2011, p. 11) and 'enable an innovative and caring environment for health professional development and patient care' (Matsoso and Strachan, 2011, p. 12). The strategic direction is captured under three themes: 1) supply of health professionals and equity of access; 2) education, training and research; and 3) working environment of the health workforce (leadership and management, human resource management, ensuring quality care, Information for planning, workforce planning capacity and structures)
- *Global strategy on human resources for health: workforce 2030* (WHO, 2016c, p. 8) has one of its key objectives, the 'optimize performance, quality and impact of the health workforce through evidence-informed policies on human resources for health, contributing to healthy lives and well-being, effective universal health coverage, resilience and strengthened health systems at all levels'.
- The *Framework on IPCHS* also speaks of an 'enabling environment' which includes strengthening leadership and management for change and reorienting the health workforce, focusing on skills mix, training, multi-professional teams, improving working conditions and compensation mechanisms and provider support groups.

With respect to organisational and management interventions for building provider trust in patients and management, the following recommendations are suggested:

- Strengthening the management and leadership competencies of facility managers
- Building an enabling and caring work environment for all healthcare providers with an additional focus on CCWs
- Fostering teamwork in TB and TB/HIV integrated services
- Promoting patient recognition and acknowledgment of providers.

### *Strengthening the management and leadership competencies of facility managers*

This study has identified challenges in management and leadership practices which adversely impacted provider morale, overall staff and TB/HIV team cohesion and provider performance.

Strengthening the management and leadership skills of facility managers, which communicate and demonstrate both interpersonal (i.e. respect, fairness, constructive feedback, care) and technical competencies and practices (i.e. planning and budgeting, analysing health information), are critical for building a more inclusive organisational culture, team cohesion and motivated staff for achieving TB targets and the vision of NHI. Ensuring consistency in communication and action is critical for building integrity and trustworthiness.

The *Framework on IPCHS* (WHO, 2016b, p. 9) calls for 'new forms of collaborative leadership that help to bring together multiple stakeholders are needed for successful reform of health services',

and identifies transformational and distributed leadership as specific interventions. Similarly, the National Department of Health (2011b, p. 79) maintains that 'Leadership and management are required across the health workforce and at all levels of the health sector .... whilst facility managers and clinicians are also required to lead and manage at service levels'. Central to this is to recognise the vulnerability of facility managers. Opportunities through coaching, mentoring and peer-to-peer support should be considered, as well as 'action learning approaches (that include a mix of formal training, on-the-job training, mentoring and support) and to insert the learnings into routine practices and processes' (Daire *et al.*, 2014, p. 10) are critical for engendering wider organisational trust.

*Promoting an enabling and caring work environment for healthcare providers*

This study has identified key challenges in the work environment, which not only challenged the ability of healthcare providers to execute their key responsibilities with respect to patient care, but also adversely impacted their overall work experience. This confirms the National Department of Health observation that '... lack of posts in the public sector, HIV & AIDS, working conditions, workload in the public sector, workplace security, relationship with management in the public sector, morale in the workplace, risk of contracting TB, personal safety, etc.' challenge the provision of an enabling and caring work environment (2011b, p. 32).

However, although National Department of Health strategy calls for the provision of an 'optimal working environment and rewarding careers' (2011b, p. 11), there is little detail regarding focus areas, key actions and how best to incorporate gender into a strategy for the workforce that is predominantly female. The *Global strategy on human resources for health: workforce 2030* (WHO, 2016c) goes further in identifying key areas for action that were identified as challenges for healthcare providers in the present study. It is recommended that there be closer alignment between South Africa's human resource for health strategy and the country policy actions contained in the WHO strategy, and specifically the recommendations contained in Box 9.3 below:

### Box 9.3 Global strategy on human resources for health: workforce 2030

**Country policy options for optimizing health worker motivation, satisfaction, retention, equitable distribution and performance.**

Implementation of the 'decent employment agenda' within an enabling and gender-sensitive working environment, enhancing and promoting the safety and protection of medical and health personnel and optimizing health worker motivation, satisfaction, retention, equitable distribution and performance through the 'decent employment', an integrated package of gender-sensitive attraction and retention policies (e.g. job security, a manageable workload, supportive supervision, professional development opportunities, enhanced career development pathways, hardship allowances, and measures to improve occupational health and safety, including a working environment free from any type of violence, discrimination and harassment). (WHO, 2016c, p. 14)

In addition to the above recommendations, it is imperative that psycho-social services that support the mental health and well-being of healthcare providers are prioritised. This study and others of healthcare providers working in low-resource, high-disease burden settings in South Africa (Makhado and Davhana-Maselesele, 2016) have identified psycho-social distress as a key challenge, and either weak or absent psycho-social support and mentorship particularly for providers lower in the professional hierarchy. Whilst this study was based within a primary-care setting focusing on TB and TB/HIV services, the findings relating to psycho-social challenges faced by healthcare providers are relevant for all healthcare providers, since stress and burnout is a challenge across the health system from primary to hospital care (Matsoso and Strachan, 2011). This is also a gender issue and challenge, given that healthcare providers are predominantly female and make up the majority of those lowest in the professional hierarchy.

The recommendations made by Makhado and Davhana-Maselesele (2016) to address the health and social impact of nurses caring for PLWH in South Africa are relevant and supported here. These recommends include:

- Introduction of employee wellness programmes (EWP), which include counselling and psychological services, to support healthcare providers in dealing with stress including personal coping strategies
- Providing an enabling and supportive work environment, where healthcare providers feel empowered and safe to share their concerns
- Introduction of Stress Management Training (SMT) to better enable providers to manage their stress levels and reduce the risk of burnout.

The implementation of these recommendations is a critical demonstration of recognising and responding to the vulnerability of healthcare providers, which in turn has the potential to build their institutional trust in the public health services as a caring health institution. This not only benefits healthcare providers, but their patients too and overall performance.

### *The special case of CCWs*

Almost a decade ago, Lehmann and Matwa (2008, p. 35) in a sharp indictment of the status of CHWs in South Africa concluded, 'The health system appears to know nothing about integrating and caring for CHWs. In fact, it has so far taken great care to keep CHWs out of the system, despite increasing reliance on them'. Ten years later, this study and others (Nxumalo *et al.*, 2016) regrettably find that little has changed, both materially and organisationally, challenging the vision of a health system that is a caring social institution.

All national and provincial policy documents recognise them as a critical component of PHC outreach teams, and the bridge between the formal health system and communities for all primary care services (National Department of Health, 2010, 2011a, 2011b; Western Cape Department of Health, 2014). In supporting the integration of CCWs into the outreach teams, the National Department of Health Human Resources for Health Strategy (National Department of Health, 2011b) calls for specific agreements with respect to CCWs which include; 1) standardised scope of work, 2) required competences, 3) training and supervision package, 4) terms and conditions of service to ensure stable financial support, adequate supervision and sufficient resources. It is recommended that the implementation of these recommendations is prioritised for improving the professional status of CCWs, their performance and over-all material and mental well-being. In addition, for the successful integration of CCWs within the PHC team, the following recommendations are made. While some are contained in the national and global HRH strategies, the acute vulnerability of CCWs demands that they require restating:

- Improved supportive supervision and visibility of supervisors: CCWs struggle to 'make their voices heard' because of challenges of professional hierarchy, lack of formal qualifications and social divides including gender and race. To redress this, it is recommended that there needs to be improved supportive supervision and improved visibility of their supervisors within the formal health system.
- Integrating CCWs into the organisational structures of the formal health system: This is necessary to redress experiences of alienation. There is a need for facility managers to build an organisational culture of inclusion and cohesion through, for example, routine practices of including CCWs in staff meetings, celebrations and other social engagements.

- Creating safe working conditions: Unsupportive and unsafe working conditions were a challenge for all providers, particularly community care workers. Interventions to improve safety and working conditions (e.g. provision of uniforms, rain coats, boots, air-time) are essential for building trust in the employing organisation. Unless the working conditions are addressed, organisational commitment and retention will remain a challenge.
- Valuing CCWs: Facility and district level interventions for raising the profile and increasing recognition of CCWs.
- Increasing the number of male CCWs: CCWs are predominantly female, and there is a need for gender diversity in the overall profile to address issues of gender-concordance between healthcare providers and patients and gender-based safety, which impact women.

#### *Fostering teamwork in TB and TB/HIV integrated services*

As observed in this study, when services between vertical programmes such as TB and HIV are integrated, while there is potential for improved organizational and service delivery efficiencies and patient access, these benefits are challenged by poor communication, duplication of information systems and poor overall management. Effective teamwork is essential for a TB and TB/HIV integrated model of care including the PHC outreach teams. As noted earlier, achievements of national TB targets are dependent on the effective performance of a multi-disciplinary team. Therefore, there is a greater need for improved management, communication and co-operation between the two services. The *Framework on IPCHS* recommends that for their effective working, teams need to be 'supported with adequate processes of work, clear roles and expectations, guidelines, opportunities to correct competency gaps, supportive feedback, fair wage, and a suitable work environment and incentives' (WHO, 2016b, p. 9). These recommendations are relevant in light of the findings of this study. In addition, the role of management in building trust through recognition, supportive feedback and fair practices is essential for building trust and fostering teamwork and cohesion.

#### *Promoting patient recognition and acknowledgment of providers*

This study has noted the importance of mutual trust, which emerges in the patient-provider relationship when mutual vulnerability is acknowledged. Okello and Gilson (2015) identify greater patient responsibility, patient respect and appreciation towards healthcare providers as important elements of trust which motivate healthcare providers. In low-resource, high-disease burden settings, where high workloads and staff shortages contribute to burnout and attrition, patient and community practices which promote respect and appreciation of healthcare providers, not only strengthen mutual trust but also enhance intrinsic motivation.

With respect to South Africa, media coverage of the public sector and healthcare providers has been largely negative. This is justified and important in light of the abuse of patients by providers that has been observed across the country (Jewkes *et al.*, 1998; Honikman *et al.*, 2015). At the same time, there is an urgent need for the media to balance the negative stories with those which recognise healthcare providers as caring and committed professionals. This should be supported by community level engagement, working with community based groups and community leaders (e.g. churches and mosques) to highlight the role of healthcare providers, and also bring attention to challenges they face in the community (e.g. safety).

## **Research learnings**

In this section, I will first reflect on insights gained from the research approach for the field of health policy and systems research, then move on to a brief discussion of learnings generated through this study about how to investigate trust, and finally conclude with ideas for future research.

### ***Research approach***

The rationale for selecting a case study approach for this study has been described in detail in the methods section. However, it is important to restate that the case study approach is especially appropriate when studying social systems where context is multi-layered, and the boundaries between phenomena and context are not clearly evident (Yin, 2014). Given its recognition of the health system as a social system of this kind (Sheikh *et al.*, 2011) such an approach is vital for HPSR; and this study demonstrates the value of case study work in HPSR, as well as strategies for conducting such research.

As in this research, the case study approach allows for and even requires a multi-disciplinary research approach. In the present study, a diverse composition of social scientists was involved in the research (i.e. social development, social work, anthropology, health policy and systems research, and health economics). Rich data was generated through the use of diverse data collection tools (observations, in-depth interviews and focus group discussions), as well as by engaging with different respondent groups (i.e. patients, providers, managers) and different spaces of research focus (e.g. patient-provider interactions in the treatment room and community, provider-provider interactions). Moreover, phasing the interviews and FGDs after facility and community observations, provided the opportunity for probing into events and relationships documented through observation.



The generation and use of thick description, which locates complex events and social relationships in the context of experiences and meanings relating to events by different actors, is an important contribution to the field of health policy and systems research. Qualitative research, and specifically the use of thick descriptions or stories, has the potential to capture and convey to the reader the depth and complexity of the health system as a living and breathing organism, and the wealth of relationships which are embedded within it. Documenting and seeking to understand these relationships and the lived experiences of the key actors (i.e. patients and providers) at the front-line of implementation, through vivid and human stories, is critical for extending our understanding of the often-observed gap between policy and practice.

To be able to gain the insight necessary for constructing thick description, prolonged engagement in the study sites is imperative. Although prolonged engagement as an approach in ethnography requires extended periods of time, even years, in the field, this is not always feasible in health policy and systems research. In this study, the period of engagement was approximately 12 weeks in each facility, and the depth of engagement was extended through the presence of a research team rather than a single researcher. During this time, while it cannot be claimed that the team were integrated into the life of the health facility, the team was able to foster relationships with both patients and providers. Equally important, the team developed a deeper appreciation of the workings and complex web of relationships within the system. Detailed field notes and observations from multiple perspectives allowed the compilation of thick description of key events and relationships in constructing the narrative for each of the case studies. An iterative analysis approach, involving both inductive and deductive analysis, captured through an audit trail of codes and quotes, strengthened the confirmability and dependability of the findings. Preparing detailed case reports underpinned the cross-case analysis that supported rigorous interpretation of complex phenomena, such as those examined here. The cross-case analysis allowed for comparing and contrasting findings across different contexts. Detailed case reports of the workings of the facility and features of the context allowed for the building of explanations of differences across cases, and development and refinement of concepts (Yin, 2014).

### ***Investigating trust***

Considering the relevance of trust in health systems, but the continuing dearth of trust-related research, particularly in LMICs, this study has shown the particular value of qualitative research approaches for generating, deepening and extending understandings of the workings and complexity of trust (and trustworthiness, gender and vulnerability) in specific contexts. Such approaches enable a richly contextualised understanding of the relationships in which trust and gender are embedded,

and the complex set of influences over vulnerability and trustworthiness on the part of patients and providers.

However, for population-based generalizability, large-scale investigation using quantitative approaches is required (Goudge and Gilson, 2005). As Goudge and Gilson (2005, p. 1449) indicate, quantitative approaches are relevant for ‘... generat[ing] data that can be used to assess the statistical significance of different determinants to levels of trust, and the association of trust with different outcomes’. However, qualitative approaches have an important role here too. Stevens and Palfreyman (2012) argue that a bottom-up methodology using qualitative approaches is critical for informing the design of population-based survey tools, and ensuring their content and face validity. Tools informed by qualitative approaches such as the present study, which through for example interviews and FGDs, incorporate the voice and language of participants (i.e. patients and providers), will more likely ‘contain appropriate language and terminology and the dimensions will be of relevance to the population being studied’ (Stevens and Palfreyman, 2012, p. 993).

### ***Future research***

Overall, the case study approach, combined with the use of diverse data collection tools and an iterative approach to data analysis, with research undertaken by a multidisciplinary team, has merit for studying treatment adherence, trust, gender and vulnerability in the health system, within South Africa and globally. This study has developed and extended an initial conceptual framework of trust (Gilson *et al.*, 2005) to encompass and highlight more prominently the role of gender, vulnerability and trustworthiness in the public health system, and the pathways leading to trust, adherence and other related outcomes. This conceptual framework requires further application and refinement to improve our theoretical understanding, and equally importantly, to inform policy and programme decisions in South Africa and other contexts, where the health system is reframed as a social institution underpinned by values of trust. The study limitations (Chapter 4) and management and organisational recommendations in this chapter suggest additional areas of context-rich research on trust in which the revised conceptual framework could be applied, which include:

- Different services (such as other infectious and non-communicable diseases), and interventions for gender-sensitive health care within them;
- Challenges of access to public health services for highly vulnerable groups (e.g. migrants, unemployed homeless men and women), and policy and programme interventions to address those challenges;

- Inter-sectoral action across health and other critical services (e.g. social development, policing), which address economic and psycho-social needs and improve health care access; and
- Organisational and management policies to strengthen management and leadership capacity of healthcare managers at different levels in the health system and interventions to enhance teamwork and the integration of CCWs into the formal health system.

The above examples of an emerging research agenda on trust, vulnerability and gender that addresses both patient and provider issues will become even more important and urgent as the South African government grapples with implementation of complex programmes like TB/HIV integration, operationalising its national health insurance policies and strategies for providing universal health care in the context of a changing health care environment.

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## Appendices

### Appendix 1: Ethics Approval: University of Cape Town



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences  
Faculty of Health Sciences Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
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09 July 2012

HREC REF: 310/2012

Ms V Govender  
c/o Prof L Gilson  
Health Economics Unit  
School of Public Health & Family Medicine  
FHS

Dear Ms Govender

**PROJECT TITLE: THE ROLE OF GENDER IN PATIENT-PROVIDER TRUST FOR TB TREATMENT**

Thank you for addressing the issues raised by the committee.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

**Approval is granted for one year till the 28 July 2013.**

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

*Signed*

**PROFESSOR M. BLOCKMAN**  
**CHAIRPERSON, HSF HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA),  
satisfaction

## Appendix 2: Ethics Approval: City Health



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E-mail: [Helene.visser@capetown.gov.za](mailto:Helene.visser@capetown.gov.za)  
Website: <http://www.capetown.gov.za>  
Ref:  
Filename: G:\Research\2012\Govender\10312.docx

### CITY HEALTH — Specialised Health

2012-07-10

re: "The role of gender in patient-provider trust for TB treatment". Researchers: Veloshnee Govender, Health Economics Unit, School of Public Health and Family Medicine, University of Cape Town (ID NO: 10312)

Dear Ms Govender

Permission has been granted to do your research as per your protocol at the following facilities.

#### Klipfontein Sub District: Contact People

Heideveld Clinic  
Mr K Nkoko (Sub District Manager)  
Tel: (021) 630-1667/ 082 433 1332  
Mrs T Nojaholo (Head: PHC & Programmes)  
Tel: (021) 630-1626/ 084 220 0133

#### Northern Sub District: Contact people

Scottsdene Clinic  
Mr A Zimba (Sub District Manager)  
Tel/Cell: (021) 980-1230 / 084 627 2425  
Mrs P Hendricks (Head: PHC & Programmes)  
Tel/Cell: (021) 980-1211 / 084 300 0558

#### Southern Sub District: Contact People

Claremont and Wynberg Clinics  
Mrs L Bakana (Sub District Manager)  
Tel: (021) 710-8295/ 083 333 4942  
Mrs B van Niekerk (Head: PHC & Programmes)  
Tel: (021) 710-9383/ 082 821 7361

#### Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinics and its patients must be arranged with the relevant Managers such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 3 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (10312). Please use this in any future correspondence with us.

Thank you for your co-operation and please contact me if you require any further information or assistance.

## Appendix 3: Facility Observation Poster



### Facility Observation in Progress

#### TO All Staff, Patients and Observers

This facility is currently being observed by researchers from the Health Economics Unit (University of Cape Town). This observation is part of a research project trying to understand the experiences of patients and health care providers in this clinic. We will be observing day-to-day functioning of the facility.

The name of the facility and individuals observed will not be used in the research report. We will keep all information relating to what people have provided confidential. Permission to carry out this project has been obtained from the provincial and local departments of health and management of this facility. Ethical approval for this study has been obtained from the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town.

If you have any questions, concerns or complaints you can contact the Principal Investigator of the project:

Veloshnee Govender (Health Economics Unit, University of Cape Town, Cape Town, Tel No: 021 406 6752, Fax No: 021 448 8152, Email:

[veloshnee.govender@uct.ac.za](mailto:veloshnee.govender@uct.ac.za)

OR

contact the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town, which oversees the ethical aspects of this study (021 406 6338).

## **Appendix 4: Informed Consent for Patients Participating in a Focus Group Discussion**

### **Informed Consent for Patients Participating in a Focus Group Discussion**

This informed consent form is for patients receiving TB treatment at clinics in Cape Town and who are invited to participate in a research project, titled “Research on the experience of Health Care Workers and Patients in the context of TB treatment”.

Name of Principle Investigator: Veloshnee Govender

Name of Organization: Health Economics Unit, School of Public Health, University of Cape Town

Contact number: 021 4066752; veloshnee.govender@uct.ac.za

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Informed Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

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### **INFORMATION SHEET**

We **[names]** are from the Health Economics Unit at the University of Cape Town and we are interested in learning about your experiences of receiving TB treatment at this clinic. This research is taking place in clinics in Cape Town, including this one. You are being invited to take part in this research because your experience as a TB patient can contribute much to our understanding and knowledge of the type of care that patients receive. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Everything you say here will be kept confidential and anonymous – no-one will ever know what you personally said (only what everybody's combined responses are). While we cannot stop or prevent participants who were in the group from sharing things that were said, we will ask everyone here to please keep the confidence of the group. Is everyone happy to do that?

We are interested in hearing what you think and feel about each topic. There are no right or wrong answers. We expect that many of you will have different points of view. I will start the FGD by asking some general questions to get the discussion going. We will be recording this session to get everything down.

**There will be no other risks to you from taking part in these focus group discussions. There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the care TB patients receive. You will not be provided any incentive to take part in the research. However, we will provide you with a token of thanks and you will receive light refreshments.**

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Marc Blockman at the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee, which is an independent committee established to help protect the rights of research participants, on telephone number 021 4066492.

Any questions before we start?

---

## **Consent Form**

***[Instruction to facilitator: Each participant in FGD is required to sign a separate consent form]***

I agree to participate in this research project. I have read [or it has been read to me] this consent form and the information it contains. I had the opportunity to ask questions. I agree that my responses be used for research on condition that my privacy is respected, subject to the following:

I understand that I will not be identifiable in any way in the research

I understand that I am under no obligation to take part in this project

I understand I have the right to withdraw from this project at any stage

**I agree to let you: take notes during the interview and record the interview [delete as appropriate]**

Signature and name of participant:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_



Signatures and name of person who sought consent:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Date: \_\_\_\_\_ **Day/month/year**

## Background information

Age: \_\_\_\_\_

Sex: \_\_\_\_\_

Marital status: \_\_\_\_\_

Other household members: # of adults \_\_\_\_\_ # of children \_\_\_\_\_

Residence: \_\_\_\_\_

Source of income:

Wages/Salary (self)
Wages/Salary (other household members)
Grants (DG, CSG, FCG)
Old Age Pension

If employed, type of employment: \_\_\_\_\_

Previous episodes with TB: \_\_\_\_\_

Duration of TB treatment in the clinic: \_\_\_\_\_

## **Appendix 5: Informed consent for in-depth interviews with patients**

### **Informed Consent Form for Patients Participating in an In-Depth Interview**

This informed consent form is for patients receiving TB treatment at clinics in Cape Town and who are invited to participate in a research project, titled “Research on the experience of Health Care Workers and Patients in the context of TB treatment”.

Name of Principle Investigator: Veloshnee Govender

Name of Organization: Health Economics Unit, School of Public Health, University of Cape Town

Contact number: 021 4066752; veloshnee.govender@uct.ac.za

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Informed Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form.

## Part I: Information Sheet

"My name is \_\_\_\_\_. I am from the Health Economics Unit at the University of Cape Town, working on a research project trying to understand the experiences of TB patients and health care providers in this clinic. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

This research is taking place in clinics in Cape Town, including this one. You are being invited to take part in this research because your experience as a TB patient can contribute much to our understanding and knowledge of the type of care that patients receive.

The interview will be totally confidential, so you should know you can tell me anything you feel comfortable with and I will never tell anyone in this clinic or anywhere else, unless it puts someone in danger. I also promise that I will not judge anything you say, and you cannot get into trouble for saying it. Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this clinic will continue and nothing will change. You may change your mind later and stop participating even if you agreed earlier.

**There will be no other risks to you from taking part in these interviews. There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the experiences of TB patients and health care providers. You will not be provided any incentive to take part in the research. However, we will provide you with a token of thanks and you will receive light refreshments.**

With your permission then, I would like to tape record the interview so I can remember it better later. The consent form for this and for taking part in the interview should come with this document for you to sign if you agree. Your participation is entirely voluntary and you can withdraw at any time. Please let me know if there is anything you do not understand. **The interview will probably take between 1-1.5 hours.**

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Marc Blockman at the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, which is an independent committee established to help protect the rights of research participants, on telephone number 021 4066492.

Any questions before we start?

**Consent Form: Research on the experience of Health Care Workers and Patients in the context of TB treatment**

I agree to participate in this research project. I have read [or it has been read to me] this consent form and the information it contains. I had the opportunity to ask questions. I agree that my responses be used for research on condition that my privacy is respected, subject to the following:

I understand that I will not be identifiable in any way in the research

I understand that I am under no obligation to take part in this project

I understand I have the right to withdraw from this project at any stage

**I agree to let you: take notes during the interview and record the interview [delete as appropriate]**

Signature and name of participant:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Signatures and name of person who sought consent:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Date: \_\_\_\_\_ **Day/month/year**

**Background information**

Age: \_\_\_\_\_

Sex: \_\_\_\_\_

Marital status: \_\_\_\_\_

Other household members: # of adults \_\_\_\_\_ # of children \_\_\_\_\_

Residence: \_\_\_\_\_

Source of income:

Wages/Salary (self)
Wages/Salary (other household members)
Grants (DG, CSG, FCG)
Old Age Pension

If employed, type of employment: \_\_\_\_\_

Previous episodes with TB: \_\_\_\_\_

Duration of TB treatment in the clinic: \_\_\_\_\_

## **Appendix 6: Informed consent for Health Care Providers participating in a Focus Group Discussion**

### **Informed Consent Form for Health Care Providers participating in a Focus Group Discussion**

This informed consent form is for Health Care Providers involved in the provision of care for TB patients at clinics in Cape Town and who are invited to participate in a research project, titled “Research on the experience of Health Care Workers and Patients in the context of TB treatment”.

Name of Principle Investigator: Veloshnee Govender

Name of Organization: Health Economics Unit, School of Public Health, University of Cape Town

Contact number: 021 4066752; veloshnee.govender@uct.ac.za

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Informed Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

## INFORMATION SHEET

We **[names]** are from the Health Economics Unit at the University of Cape Town, and we are interested in learning about your work in this clinic generally and also about your experience working with TB patients. We would like to find out more about your experiences working here in the clinic. Everything you say here will be kept confidential and anonymous – no-one will ever know what you personally said (only what everybody's combined responses are). While we cannot stop or prevent participants who were in the group from sharing things that were said, we will ask everyone here to please keep the confidence of the group. Is everyone happy to do that?

We are interested in hearing what you think and feel about each topic. There are no right or wrong answers. We expect that many of you will have different points of view. I will start the FGD by asking some general questions to get the discussion going. We will be recording this session to get everything down.

**There will be no other risks to you from taking part in these focus group discussions. There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the care TB patients receive. You will not be provided any incentive to take part in the research. However, we will provide you with a token of thanks and you will receive light refreshments.**

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Marc Blockman at the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee, which is an independent committee established to help protect the rights of research participants on telephone number 021 4066492

Any questions before we start?



**Consent Form: Research on the experience of Health Care Workers and Patients in the context of TB treatment**

***[Instruction to facilitator: Each participant in FGD is required to sign a separate consent form]***

I agree to participate in this research project. I have read [or it has been read to me] this consent form and the information it contains. I had the opportunity to ask questions. I agree that my responses be used for research on condition that my privacy is respected, subject to the following:

I understand that I will not be identifiable in any way in the research

I understand that I am under no obligation to take part in this project

I understand I have the right to withdraw from this project at any stage

**I agree to let you: take notes during the interview and record the interview [delete as appropriate]**

Signature and name of participant:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Signatures and name of person who sought consent:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Date: \_\_\_\_\_ **Day/month/year**

**Background information**

Age: \_\_\_\_\_

Sex: \_\_\_\_\_

Position in the clinic: \_\_\_\_\_

Length of service in the clinic: \_\_\_\_\_

Length of time working with TB patients: \_\_\_\_\_

Length of time working in health care (as a nurse or DOTS supporter etc.):  
\_\_\_\_\_

What type of work did you do before working in the clinic? (Answer in relation to your last employment)

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## **Appendix 7: Informed consent for in-depth interviews with healthcare providers**

### **Informed Consent Form for Health Care Providers participating in an In-depth Interview**

This informed consent form is for Health Care Providers involved in the provision of care for TB patients at clinics in Cape Town, and who are invited to participate in a research project, titled “Research on the experience of Health Care Workers and Patients in the context of TB treatment”.

Name of Principle Investigator: Veloshnee Govender

Name of Organization: Health Economics Unit, School of Public Health, University of Cape Town

Contact number: 0214066752; veloshnee.govender@uct.ac.za

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Informed Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

## Part I: Information Sheet

My name is \_\_\_\_\_. I am from the Health Economics Unit at the University of Cape Town, working on a research project trying to understand the experiences of TB patients and health care providers in this clinic. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

This research is taking place in clinics in Cape Town, including this one. You are being invited to take part in this research because your work and personal experience as a TB health care provider can contribute much to our understanding and knowledge of the type of care that patients receive.

The interview will be totally confidential, so you should know you can tell me anything you feel comfortable with and I will never tell anyone in this clinic or anywhere else, unless it puts someone in danger. I also promise that I will not judge anything you say, and you cannot get into trouble for saying it. Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

**There will be no other risks to you from taking part in these interviews. There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the experiences of TB patients and health care providers. You will not be provided any incentive to take part in the research. However, we will provide you with a token of thanks and you will receive light refreshments.**

With your permission then, I would like to tape record the interview so I can remember it better later. The consent form for this and for taking part in the interview should come with this document for you to sign if you agree. Your participation is entirely voluntary and you can withdraw at any time. Please let me know if there is anything you do not understand. **The interview will probably take between 1-1.5 hours.**

“If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Marc Blockman at the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee which is an independent committee established to help protect the rights of research participants on telephone number 021 4066492

Any questions before we start?

## Consent Form

I agree to participate in this research project. I have read [or it has been read to me] this consent form and the information it contains. I had the opportunity to ask questions. I agree that my responses be used for research on condition that my privacy is respected, subject to the following:

I understand that I will not be identifiable in any way in the research

I understand that I am under no obligation to take part in this project

I understand I have the right to withdraw from this project at any stage

**I agree to let you: take notes during the interview and record the interview [delete as appropriate]**

Signature and name of participant:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Signatures and name of person who sought consent:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Date: \_\_\_\_\_ **Day/month/year**

**Background information**

Age: \_\_\_\_\_

Sex: \_\_\_\_\_

Position in the clinic: \_\_\_\_\_

Length of service in the clinic: \_\_\_\_\_

Length of time working with TB patients: \_\_\_\_\_

Length of time working in health care (as a nurse or DOTS supporter etc.):  
\_\_\_\_\_

What type of work did you do before working in the clinic? (Answer in relation to your last employment)

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**Informed Consent Form for Health Care Providers participating in a Focus Group Discussion**

This informed consent form is for Health Care Providers involved in the provision of care for TB patients at clinics in Cape Town and who are invited to participate in a research project, titled “Research on the experience of Health Care Workers and Patients in the context of TB treatment”.

Name of Principle Investigator: Veloshnee Govender

Name of Organization: Health Economics Unit, School of Public Health, University of Cape Town

Contact number: 021 4066752; veloshnee.govender@uct.ac.za

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Informed Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

## INFORMATION SHEET

We **[names]** are from the Health Economics Unit at the University of Cape Town and we are interested in learning about your work in this clinic generally and also about your experience working with TB patients. We would like to find out more about your experiences working here in the clinic. Everything you say here will be kept confidential and anonymous – no-one will ever know what you personally said (only what everybody's combined responses are). While we cannot stop or prevent participants who were in the group from sharing things that were said, we will ask everyone here to please keep the confidence of the group. Is everyone happy to do that?

We are interested in hearing what you think and feel about each topic. There are no right or wrong answers. We expect that many of you will have different points of view. I will start the FGD by asking some general questions to get the discussion going. We will be recording this session to get everything down.

**There will be no other risks to you from taking part in these focus group discussions. There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the care TB patients receive. You will not be provided any incentive to take part in the research. However, we will provide you with a token of thanks and you will receive light refreshment.**

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Marc Blockman at the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee which is an independent Committee established to help protect the rights of research participants on telephone number 021 4066492

Any questions before we start?



**Consent Form: Research on the experience of Health Care Workers and Patients in the context of TB treatment**

***[Instruction to facilitator: Each participant in FGD is required to sign a separate consent form]***

I agree to participate in this research project. I have read [or it has been read to me] this consent form and the information it contains. I had the opportunity to ask questions. I agree that my responses be used for research on condition that my privacy is respected, subject to the following:

I understand that I will not be identifiable in any way in the research

I understand that I am under no obligation to take part in this project

I understand I have the right to withdraw from this project at any stage

**I agree to let you: take notes during the interview and record the interview [delete as appropriate]**

Signature and name of participant:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Signatures and name of person who sought consent:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Date: \_\_\_\_\_ **Day/month/year**

**Background information**

Age: \_\_\_\_\_

Sex: \_\_\_\_\_

Position in the clinic: \_\_\_\_\_

Length of service in the clinic: \_\_\_\_\_

Length of time working with TB patients: \_\_\_\_\_

Length of time working in health care (as a nurse or DOTS supporter etc.):  
\_\_\_\_\_

What type of work did you do before working in the clinic? (Answer in relation to your last employment)

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## Appendix 8: Focus group topic guide for patients

### Part I: Information Sheet

Name of facility in which group interviewed: _____	Date _____
Time discussion started: _____	Time ended: _____
Participant summary: No. of women: _____	No. of men: _____ Total No.: _____
Name(s) of facilitator(s): _____	

### FGD Questions

1. I would like to hear from you when and how you became a patient at this clinic.
2. How is your life now different to how it was before you got ill with TB?
3. How do these factors affect you taking your treatment?
4. What or who helps you complete your treatment? These could relate to you, your family and friends and the clinic.
5. Why do you take your treatment on your own?
6. How do you feel about taking treatment on your own instead of coming to the clinic or from a DOTS supporter?
7. Tell me about an experience that you cannot forget at the clinic that left you feeling happy/unhappy and dis/encouraged you to stay on treatment.
8. If you could change anything about TB treatment in this clinic, what would you change?
9. From your experience, do clinic staff behave differently with different patients?
10. If you were a man/woman (opposite of what they are), in what ways would staff in the clinic staff behave differently with you?
11. If you could decide, would you rather have a male or female nurse? Why?
12. If a family member had TB, what would you tell them to help them prepare for coming to the clinic?

## Appendix 9: In-depth-interview topic guide for patients

### In-depth interview guide with TB patients

1. How did you become a TB patient at this clinic? *[probe for symptoms, how do you believe you got TB, when and where it diagnosed, any delays in getting tested, why did he/she choose this clinic, past experience]*
2. Have you previously received services in this clinic? *Probe for how were you treated? How did that influence your decision to come back to the clinic when you got TB? Besides this clinic, have you ever sought treatment from anywhere else? And if yes, who and why? [probe for private doctors, pharmacists, traditional healers]*
3. How is your life now different to how it was before you got ill with TB? *[Probe for childcare, community commitments, other work, searching for work]*
4. What are the things about your life that affect your taking/completing your treatment?  
*[Probe for barriers and facilitators: socio-economic factors, distance from clinic or DOTS supporter, operating hours and work/household responsibilities, community issues, stigma, social support from family, friends, work colleagues; Probe for examples: e.g. family or work crisis, violence in the community; how was the situation handled; how did they feel about the way it was handled; how did it affect their treatment, how could it have been handled differently; how did the clinic and staff help]*
5. How did you feel that you would have to be on treatment for 6 months, how did you feel? *[Probe for how does being a man/women influence the treatment you receive in this clinic?]*
6. If you take your tablets under the supervision of [clinic staff or DOTS supporter], how was the decision made and why did you agree? *[Probe 1) for their role in the decision, how they feel about the decision, the role of staff in the decision; 2) how it affects their behaviour; and 3) what would they would they prefer and why?]*
7. If you experience any side-effects from the tablets, what will you do? *(side effects include nausea, vomiting, loss of appetite, jaundice, dark urine, fever). [Probe for whether they will come back to the clinic and report it to the staff, stop treatment because they feel that the staff had given them the incorrect medication, seek care elsewhere].*
8. What could the clinic do to help you complete your TB treatment? *[Probe for examples]*
9. If you could change anything about TB treatment in this clinic, what would you change?
10. Describe an experience [in the clinic if on facility DOTS OR on community DOTS] that left you feeling happy/good and encouraged you to stay on treatment. What made it good? *[Probe for examples and aspects of the clinic they like/like less including training/skills of staff; staff-patient relationships; availability of tabs, medications, supplies and equip; flexibility of the treatment programme; facility hours, being observed taking treatment, waiting time, waiting rooms etc.]*
11. Describe an experience [in the clinic if on facility DOTS OR on community DOTS] that left you feeling unhappy/bad and discouraged you from staying on treatment? *[Probe for what made it bad? How did it make them feel about the provider and the clinic? Did they report it? To whom? How was it handled? Did they stop coming back to the clinic and sought care elsewhere?]*

12. For male patients: How does it feel coming to a clinic where most of the patients are women and children and the staff are women?
13. If a family member or friend had TB, would you suggest that they come to this clinic? *[Probe for why]*
14. What do you like most about [the TB staff if on facility DOTS OR the DOTS supporter if on community DOTS] that encourages you complete your treatment? *[Probe for 1) staff are caring, attentive, listen, answers any questions that the patient has, is available, does not keep the patient waiting, respects personal boundaries, empathetic and 2) the consequences for their behaviour]*
15. What do you like least about [the TB staff if on facility DOTS OR the DOTS supporter if on community DOTS] that discourages you from completing your treatment?
16. From your experience in this clinic, do staff behave differently with different patients? *[Probe for examples and for differences in terms of gender, race, socio-economic status, age; how does it make you feel]*
17. From your experience in this clinic, in what ways do male and female clinic staff treat patients differently?
18. From your experience, if the patient and staff (nurse, DOTS supporter) are both men/women, in what ways does it influence their behaviour and the patient's ability to complete treatment?
19. If you could choose, would you choose a male or female nurse/DOTS supporter? Why?
20. Do you think having TB affects the way patients and clinic staff/DOTS staff behaves towards you? If so, how?
21. Do you think having TB has changed how people behave towards you? *[Probe for 1) household members, friends, neighbours, co-workers, employer and others outside the household behave towards you; and 2) what have been the changes?]*
22. What gives you the strength to complete your treatment? *[Probe for intrinsic motivation, support of family, friends, DOTS supporters, clinic TB staff]*

## Appendix 10: Focus group discussion with healthcare providers

Name of Facility in which Group Interviewed: _____ Date: _____
Time discussion started: _____ Time ended: _____
Participant summary: No. of women: _____ No. of men: _____ Total No.: _____
Name(s) of Facilitator(s): _____

### FGD Guide Healthcare Providers

I would like to start the discussion by asking people about their experience working as CCWs.

1. What are some of the reasons that people decide to become CCWs?  
*Probe for financial reasons, working with community, career in nursing/healthcare*
2. What qualities and characteristics should CCWs have to be able to carry out their work with patients successfully?  
*Qualities might relate to interpersonal qualities (e.g. communication skills, empathy, respect, known/respected in the community); characteristics might include free time, male/female*
3. Is it easier for men or women to be CCWs? In what ways is it easier or more challenging?  
*Probe for ways in which being a man/woman helps/enables and ways in which it constraints; women as caregivers, nurturers, mothers; concerns over personal safety in relation to community issues e.g. drugs, gang-related violence; interpersonal relationships with client; multiple roles (household, financial and CCW responsibilities), sexual harassment*
4. How does working as a CCW affect people's personal/domestic lives?  
*Probe for childcare, community commitments, other work, searching for work; personal safety, relationships with partners. Probe for older/younger women whether there are different challenges? If they have listed challenges, how have they overcome some of the challenges that they have listed?*
5. How does the community see CCWs?  
*Probe for issues of respect/ standing/status in community; infection, stigma, personal safety. If they have listed challenges, how have they overcome some of the challenges that they have listed?*
6. What are some of the challenges in the community which affect the work of CCWs?  
*Probe for drugs, gang-related violence, concerns over physical safety when following up patients; support networks including family, community, religious groups, familiarity with community. How do CCWs overcome these challenges?*

7. What are the factors that affect TB patients' ability to take their treatment?  
*Probe for poverty, unemployment; lack of food; social problems relating to substance abuse, domestic violence; household responsibilities; community issues drugs, gang-related violence, concerns over physical safety etc; proximity to a CCW; lack/ presence of personal responsibility/motivation; side-effects from the treatment; how does each of these issues affect their ability to adhere to treatment? Do men and women experience and cope differently with these challenges?*
8. From people's experience, do male and female patients behave differently with CCWs? In what ways?  
*Probe for interpersonal issues (communication practices, disclosure of information etc).*
9. From people's experience, are men or women more treatment compliant/adherent? In what ways? What are the underlying reasons?
10. I would like people to think about a patient that they admire most and will always remember. This was a patient who struggled to take his/her treatment, but managed to overcome their illness and challenges.  
*Describe the patient and his/her story, what quality did this patient have that they admire, probe for whether these qualities are gendered; how did the patient cope in a way that was remarkable, in what way did the participant and others assist the patient, what was their relationship with the patient like? How does that motivate them to continue their work? [If the participant mentioned a man, then ask other participants for an example of a woman or vice-versa]*
11. How do people feel about working in this clinic?  
*Probe for aspects that they like/dislike in relation to: patient load; communication, interpersonal relations with facility staff; support from clinic staff in relation to patients*  
*Probe for how each of the issues raised affects their work and their ability to carry out their work, paying attention to issues of gender (norms, roles, relations)? In response to the challenges that they have identified in the previous question, how have they managed to overcome some of those challenges?*
12. In what ways do staff from the clinic help them carry out your work?
  - *Probe for training, supervision, refresher courses, remuneration, counselling, dealing with challenging patients?*
13. If there is anything about the job that people could change, what would it be?
  - *Probe for training, remuneration, counselling, mentorship, dealing with challenging patients*
14. I would like people to think of a time when a CCW was recognised for his/her work and contribution? [ by patients, co-workers, supervisors]
  - *Describe the story, what did the person do, how was the person recognised, what impact did this have on the person and the rest of the CCWs/staff? If the participant recounts a story of recognition by a patient, probe for stories about co-workers, supervisors etc.*

## Appendix 11: In-depth interviews with healthcare providers

### In-depth interview guide with TB providers

1. Tell me about yourself. Who is \_\_\_\_\_ [provider name]?
2. How did you come to be working as a \_\_\_\_\_ [profession]?  
*[Probe for the reasons that lead to this profession?]*  
How and when did you start working with TB patients/care?
3. Tell me about your job; what are your duties?  
*[Probe for average/typical day in the clinic?]*
4. Have you experienced TB personally? That is have either you, a family member, a close friend had TB.  
*[Probe for how does it affect their work with TB patients]*
5. How do you feel about working with TB patients? *[Probe for aspects that they like/dislike in relation to concerns over infection, patient adherence, follow-up of patients, administrative responsibilities, interactions and relationships with patients]*
6. Can you tell me a bit more about the types of relationships that you might develop with your patients?  
*[Probe for if it is important for them to develop relationships with patients and if it is easier to develop relationships with some patients compared to others]*
7. Describe your ideal patient? How do you behave towards them? *[Probe for gender, race, socio-economic status and interpersonal dynamics: understands and adheres to treatment, is actively involved in managing his/her illness, is responsible, provides all the medical information needed, keeps to appointments, respects provider's time, does not make unreasonable requests, respects personal boundaries].*
8. Describe your less than ideal patient? How do you behave towards them?
9. What issues affect patients' ability to complete their treatment? *[Probe for length of treatment, poverty, unemployment; lack of food; social problems relating to substance abuse, domestic violence; household responsibilities; community issues, drugs, gang-related violence, concerns over physical safety etc; proximity to a DOTS supporter; lack of presence of personal responsibility/motivation; side-effects from the treatment]*
10. Do male and female patients experience these issues differently? How?
11. From your experience, do male and female patients behave differently towards you as woman and do you have a different relationship with them? *[Probe for examples]*
12. From your experience, do patients behave differently depending on their race, the amount of money they have, or their religion, towards you and do you have a different relationship with them? *[Probe for examples]*
13. From your experience, are some patients better at completing their treatment than others? *[Probe for gender, race, socio-economic status, religion, employment status, substance abuse; probe for implications for interpersonal relationships between patient-provider]*



14. How does your work with TB patients affect you and your family? *[probe for concerns of risks of infection, concerns for family's health, difficulties of separating work from home, juggling work and home responsibilities]*
15. How does your personal life affect your work? *[Probe for socio-economic factors, household responsibilities, community issues and influence on work in relation to patients]*
16. In what ways does being a woman/man affect your work? *[Probe for ways in which being a woman/man helps/enables and ways in which it constrains; for women: caregivers, nurturers, mothers; concerns over personal safety in relation to community issues e.g. drugs, gang-related violence; interpersonal relationships with client; multiple roles (household, financial and DOTS responsibilities)]*
17. Has your current role changed since you have been in this post or do your responsibilities in the clinic match your job description? *[Probe for why has it changed and how the participant feels about the change]*
18. If there were anything about your job that you could change, what would it be? *[Probe for training, position in the clinic, remuneration, mentorship, working with TB patients]*
19. If there were anything about this clinic that you could change, what would it be? *[Pprobe for inter-personal relationships with colleagues, management practices; additional staff, workload]*
20. What do you like most about working at this clinic? *[Probe for specific examples in relation to work load, staff shortages, training needs, opportunities for participating in decision making, salaries, interpersonal relations with co-workers and management]*
21. What aspects of this clinic do you like less and find challenging? *[Probe for specific examples]*
22. How do these aspects of the clinic you described influence your work? *[Probe for work in relation to patients, in relation to colleagues, management]*
23. Have you ever thought of leaving this post and working in another clinic? *[Probe for why they would think of changing and what keeps them in their present position]*
24. Have you ever thought of stopping your work in health care for a non-health care post? *[Probe for why]*
25. Can you tell me a story about a time when you had a problem in the clinic that affected your work? *[Probe for examples: How was the situation handled; how did they feel about the way it was handled; how did it affect their work; how could it have been handled differently?]*
26. If a family member had TB, would you recommend that they came to this clinic? Explain.

## Appendix 12: Example of facility observations

### Notes and Reflections, 11 October 2012, Facility 1

I arrive shortly after seven, expecting today to be a busy day, because it is the doctor's day – he comes once a week on a Thursday morning. Indeed, there is a queue of 24 people lining the front of the clinic, all adults. I am wrong, though for this queue is not for the clinic, it is the line waiting for transport to take them to alternative eye clinics as the eye clinic is (as notices round the centre inform one) "closed until further notice". One taxi has, I am told, already left. There is great consternation in the queue, as many people did not know that they need copies of the IDs. One lady comes inside, saying her sister is disabled, and didn't know she needed a copy of her ID. The DOTS supporter says she will go next door and say it is her ID that she is copying (I'm not sure where next door is). The clinic itself is dead quiet. The staff slowly trickles into the staff room, making coffee and tea, eating breakfast and chatting. Worried patients from the eye clinic keep knocking on the door of the staff room for copies of their IDs. Eventually, Evan grumpily goes to make copies on the clinic fax machine. The DOTS supporter shows a side I have never seen, pulling her tongue out at demanding people as they leave the room. It sounds like, from a story she tells, both her children are mentally disabled, and living with her.

At eight thirty, things are still quiet in the clinic. The TB passage has three people: a woman, (late forties) who says she wants to test again. She has a brown striped beanie, and purple slack tracksuit pants. She is hunched, and though she seems confident enough in the space, she almost shuffles her walk. She wants to test, she says, because she has once again started coughing. (After, an hour later, she goes and does the first sputum collection. The TB nurse asks whether she needs to go through for VTC. The trainee nurse says "Sy'tie nodig vir daai nie", and whispers something in Laura's ear. Laura nods understanding, says "Oh, okay", and tells the lady to wait for an hour, and then spit again. She eventually leaves at 9:56).

A man in blue overalls (50s?) sits with his file and one large man, in his early forties leans against the door frame in the DOTS room.

Ten minutes later the man in the blue overalls goes into the DOTS rooms (where the large man still stands). In the passage, a plump woman in a bright pink top is waiting to see the doctor and be signed off – she has just finished her six months of treatment.

A young woman (18?), with black jeans and a pink head scarf sits next to me. Her name is Aisha, and she is nine months into a twelve month treatment regime. Her TB is glandular, and she is treated here and at Groote Schuur. She said she was very sick, and then made a rapid recovery, then got ill again, and now she is slowly healing. She takes her medication on her own, at home, and comes into the clinic once a month for checkups.

Another young woman, walking with attitude (and a bright pink head band) walks through to the DOTS rooms; she immediately drinks her tablets and goes out again.

During this time I inhabit the passage – things are not busy, but the DOTS room is crowded, and somehow it feels as though I would be too in the way there.

I start chatting to a man (50?), he sits hunched, and I am reluctant to start a conversation, but I do, in Xhosa, which works, and we switch to English, sometimes using Xhosa when I can express myself adequately and it will make things easier. He says he is between here and Heideveld, where he went first, and where he gets his ARVs – he was there last Thursday. He has come here because he needs to see a doctor, he has diarrhoea and his stomach is cramping. He is struggling to keep his drugs down. He says that this is his second round of TB treatment, that he started well on the last round, but then started drinking too much, and stopped taking his medication. He is worried he will do the same, so he says he is going to try to be checked into the TB hospital for the rest of his treatment, so that he can be sure to complete it properly. He says he struggles to come here, because he has no money for a taxi and must walk very slowly, stopping as he goes. He lives with his sisters who, he says, are very kind in caring for him.

9:37 The waiting room is still fairly quiet. I sit next to a mother with a very small baby – six weeks today. His mother says he is there for this injections, and some results. I say, but today is TB day, and she says that he is a

TB patient. He is listless and the mother, dressed in jeans and a black sweater says they are waiting for the results of his lumbar puncture (done at Red Cross last week). She says he is currently on preventative drugs, but the sputum test was negative. They are testing him because he is struggling with his breathing, and they suspect TB. She is there waiting with her friend (with the pink head scarf, who went through to drink her pills earlier, on her own.) When they do, eventually see Sister X, she asks them for their discharge card from Groote Schuur, she says that the file tells her nothing, she needs the letter. The mother starts out by saying she forgot the letter, but that she can't walk all the way home now, can they please help. She is told to go home, she is frustrated, and Laura stands and stares her out, and tell her to come back before 11 (I miss what happens next, but there is clearly an altercation with the records room about assistance.)

When I next see the mother and small baby (10:43) the mother is sitting in a chair in front of the records room waiting for assistance. Just sitting. I ask if she has been sorted out, and she says "Ek was nou net baie onbeskof met hulle", but she says Groote Schuur didn't give her a letter (and in contradiction) that she can't go home now. But she is crying, and clearly worried, she says the child hasn't eaten since he threw up his medicine hours ago, but he is constantly spitting out a clear viscous fluid. She says that each time after he has spat, he looks "flou". Laura comes and comments on the child, and asks whether they have been helped. The mother says they have a problem with the discharge letter, but she is worried about the child now and she explains his symptoms. Laura immediately asks whether he has a respiratory problem, "They can do that when they have a respiratory problem" she says in a very calm, comforting voice, and she takes the mother through to see the nurse.

9:40 In the DOTS room there is a young mother (Congolese by the accent?) with a large-eyed child with braids on her lap. I sit in the records room with a man, (40s), rough looking and coughing. He says he thinks he might have TB again, he has had it 3-4 times before (I can't make out whether this is the fourth, or he has had it four times), all times were successfully treated at this facility. He says he doesn't know why he keeps getting it, but his current coughs and night sweats are familiar.

10:00 a Thin boy (late teens) with a green hoodie comes in and sits down (I think he is the one that was here with his mother on Tuesday). He is very contained, and I do not chat to him. Laura comes through and greets him, "Hello Adrian!" He goes into the DOTS room with her, and stands waiting by the door. (I assume he then drinks his tablets, but do not see this, he leaves the room at 10:08)

The mother with the big-eyed child (who I assume is three or four, but is, in fact a very tall 2 year old) comes and sits in the passage. The mother is very well presented and dressed. Hair neatly back in a pony, stylishly dressed. She says her daughter is scared coming here, because she remembers having the TB skin test done, and now she doesn't trust anybody here. She says she has come for a doctor's letter, because her TB is still active, and she needs to take 2 weeks off work, while it quiets down. She has also come to pick up her tablets, which she takes on her own at home.

10:43 Lisa (the diabetic four-year old) and her mother, Trisha arrive to drink their tablets. I recognize Lisa, so am able to greet her by name, which makes starting the conversation easier. Vanessa sits down, and we chat a bit, she says Lisa (who is on her mother's lap, munching a packet of nikkaks) is on a six-month preventative treatment programme, while she has her treatment 2 months to go). Vanessa looks better today, walking on straw platforms, she is somehow more upright, and her ruddy complexion seems less a sign of alcohol today, combined with neat hair and a clarity in her movements. She says, "Ek wil net my pille drink, nou moet ek hier sit, en ek raak depressed. Ek is nie n mens met patience nie." I ask them where they live, and she says they're in the "plakkies kamp" close by. She says that Lisa is naughty, but that's what she learns from the adults around her where they live. Trisha is getting impatient, "Kan ek'ie my pille drink, die suster maak my naer," she says kind of to me, kind of to no one in particular.

11:00 Trosha gets tired of waiting, the DOTS room is empty. With a glance at the records room she goes in, finds her tablets and drinks them. She comes out and says to me, as she waits for someone to sign her card, "Dis nou n stress situasie. Wag, wag, wag vir wat moet ek nou wag? Net om my pille te drink en vir hulle sign." She says her sister has a small house shop where they live (selling cigarettes and sugar, and other small things, she shows me a packet of cigarettes in her hand), and that her sister has gone to the day hospital with her

husband. While they are not there she cares for the shop in exchange for enough money to make a pot of food. She says she can't afford for them to come back and she's not there, and she only came now because she thought it would be quick.

Laura comes into the passage, and Trisha asks her to sign, "Het jy al jou pille gedrink?" asks Laura, Trisha to go look, she can see that her container is empty. "O, Ja, sweetie pie, says Laura, jy moet nog ons n culture ook doen". "n Wat?" asks Trisha, "n spoeggetjie" says Laura. Lisa stays with me, on my lap while Trisha quickly goes through to the sputum room. At 11:08 they leave.

11:08 Only one, well dressed woman (late 30s?) with a head scarf, jeans and car keys. She is standing, rather than sitting, and is partly on her phone, waiting card in hand. I explain what I am here for, and ask if she minds answering some questions. She explains that she is there with her father (sitting around the corner), and that they have come for a checkup, he has not been very well. I ask what their experience of the facility has been, and she says, "No fine, very fine". She says that they started out a hospital but came here. She says it is better to be in a specialist facility, where they look at the patient and "it is like a photocopy of what they know". She says that until her father got TB she didn't realise that everyone can get TB, that it lives inside us all, it is just about the strength of your immune system. She goes back around the corner to sit with her father.

The man with the brown hat (4<sup>th</sup> time TB one) comes out of the DOTS room to leave. He says to me that he still needs to go to Heideveld (ARVs, I assume) and to another clinic. In the passage Sister X says to him that she is sorry, she has checked, and they have no food for adults, only pap and baby milk for children. She says he must ask again next time he comes. He leaves looking dejected, and I notice how very, very thin he is.

11:24 – Everything is very quiet. Andre, who is there to get the results of the test done on Monday arrives. He is told that he has just, just missed his wife and child (the mother with the braided, large eyed child) and later it makes sense how and why this would have happened. He is told his child's test was negative, and later I see him sitting outside the VTC rooms. In the staff room (over an early lunch – lunch and tea have merged today) there is a conversation between sister X and the VTC nurse, about him. It becomes clear that he had no idea that his wife was positive. Sister X says she doesn't understand how he didn't figure it out, she told him that if they didn't use condoms he would definitely contract HIV. She said that she asked the mother about when she found out, and she said had found out when pregnant, and she had gone through a PMTCT process. The VTC nurse says that the husband is negative, but clearly very shocked, he had no idea his wife was positive. She says "this is a domestic issue" I'm not going to say anything else. Andre, who I have always seen laughing and with a bounce in his walk leaves after 12. He is looking stormy.

While the staff are on tea/lunch a young woman (18 years, I asked) stands at the reception with her baby. Her sister is there too, but mostly waiting outside. The young woman says that "they make you wait long here" and I explain what I am doing. We chat about life and work. She asks me if I have children and when I say no, she looks down at her feet as if simply not knowing how to respond. She says that she should have written matric this year, but because of her child, she is set to write in May next year. She says that she is going to go to the police force when she is finished. That her sister says she is crazy, one mustn't have dreams, because you won't achieve them, so it is better not to have them. "But I am going to dream, and I am going to the police force". She has plans to get her driver's license and her matric certificate so that she can do this. She says that her child had TB of the glands, that they removed a gland. I don't quite understand her explanation for it, but she causally links the TB to his inoculations. We chat for some time. Eventually, there is someone in the reception (I forget who) and she goes up to ask for assistance. She gets help, and turns to me, "See now, if I hadn't asked, they would never have helped me.

12.30 The clinic is dead quiet, and I go home.

## Appendix 13: Patient and Provider Code Lists

### Patient code list for Facility 3 (source in-depth interviews)

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HU: backup of EC Patients  
File: [D:\PHD\Data Analysis\_3facilities\Patients\backup of EC Patients.hpr6]  
Edited by: Super  
Date/Time: 2017-03-22 03:22:24

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Community context  
Male patients uncomfortable in clinic  
Patient challenges queue system  
Patient challenges clinic timings  
Patient challenges unhelpful rude providers  
Patient challenges visiting clinic community violence  
Patient community support  
Patient concerned for children  
Patient drug dependency  
Patient drug side-effects  
Patient empathising with staff  
Patient everyone treated equally in the clinic  
Patient expectations of providers  
Patient family support  
Patient fear of death  
Patient feels rushed in clinic  
Patient gang member  
Patient illness experience emotions  
Patient impact of TB on family  
Patient impact on work  
Patient masks  
Patient motivation to take treatment  
Patient must prove commitment to treatment  
Patient non-adherent  
Patient not fully informed of side-effects  
Patient participation in decision making  
Patient patients must listen to HCWs  
Patient poverty  
Patient praising HCW  
Patient preferred clinic good service  
Patient preferred clinic nearest  
Patient preference for clinic DOTS  
Patient preference for female provider  
Patient preference for self-supervision  
Patient previous experience with clinic  
Patient providers are supportive  
Patient provider gender does not matter  
Patient provider technical knowledge  
Patient providers are friendly  
Patient providers are respectful  
Patient received counselling  
Patient respect provider  
Patient scared of providers  
Patient stigma  
Patient TB retreatment  
Patient TB symptoms  
Patient TB treatment did not work  
Patient unemployed  
Patient waiting time  
Trust mentioned

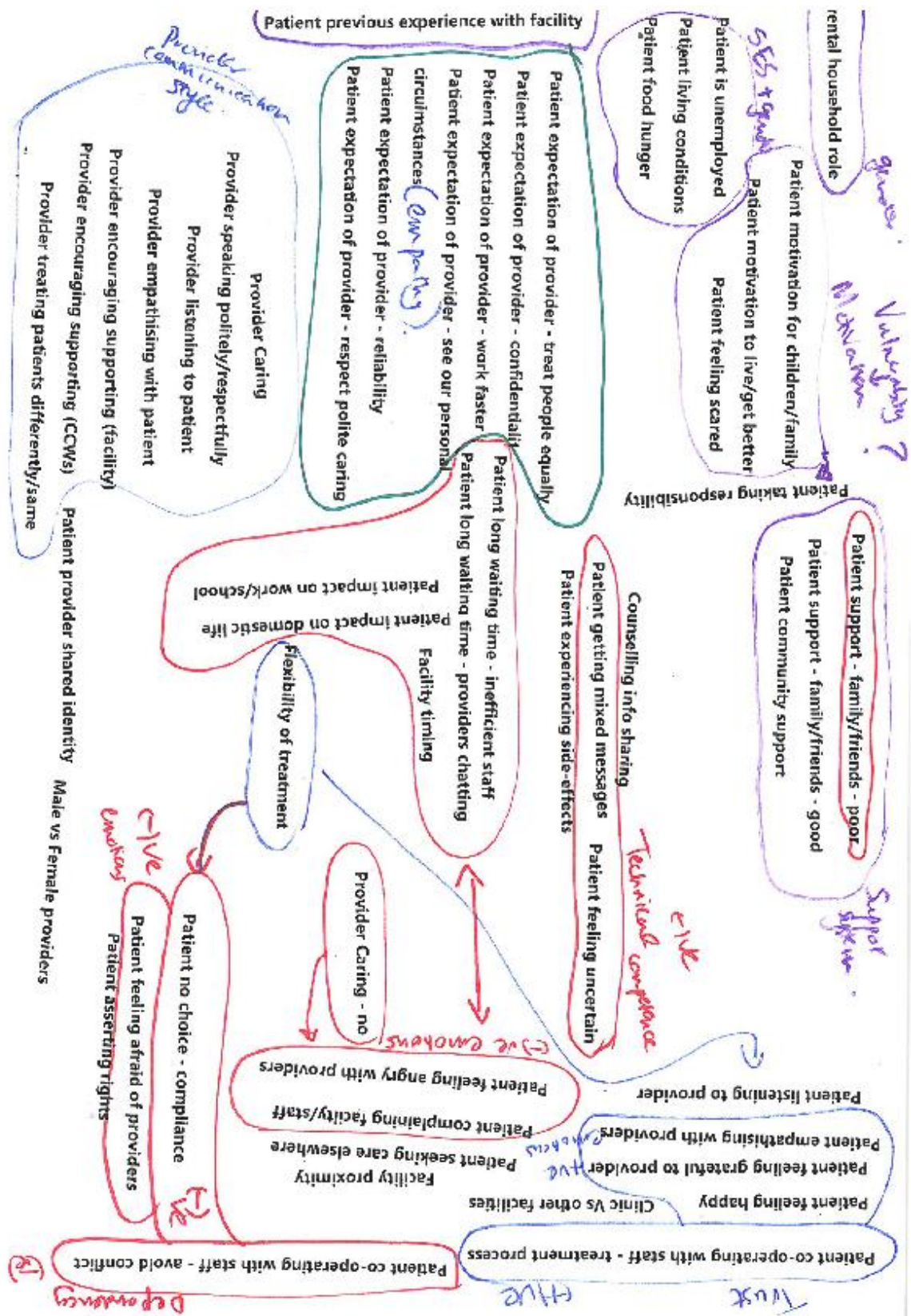
## **Provider code list for Facility 2 (source in-depth interviews)**

HU: Facility 2 providers  
File: [D:\PHD\Data Analysis\_3facilities\Providers\Facility 2 providers.hpr6]  
Edited by: Super  
Date/Time: 2017-03-22 03:31:47

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Facility reputation  
Gendered perceptions of healthcare work  
Gendered perceptions of patients  
Hierarchy in the facility  
Provider and salary  
Provider belief in God  
Provider belonging in facility  
Provider career trajectory  
Provider challenges: provider experiences not considered in policy  
Provider challenges: targets  
Provider confidentiality  
Provider empathy  
Provider expectation of patient: responsibility  
Provider expectation of patients: complaining  
Provider expectation of patients: rude disrespectful demanding  
Provider hold responsibilities  
Provider impact of work on personal life  
Provider intrinsic motivation  
Provider job description  
Provider job satisfaction  
Provider judgemental of patients  
Provider life history  
Provider listening  
Provider mentorship supervision  
Provider Patient boundaries  
Provider perception of adherence challenges  
Provider perceptions of patients being judgemental of providers  
Provider perceptions of patients fearing providers  
Provider perceptions of patients: dishonest un-cooperative  
Provider perceptions of prof competencies  
Provider personal safety  
Provider personal TB experience  
Provider personal/professional growth  
Provider recognition-appreciation by colleagues  
Provider recognition-appreciation by patients  
Provider recognition-appreciation by senior management  
Provider relationship with supervisor and management  
Provider role model  
Provider sharing personal story with patient  
Provider socioeconomic status  
Provider supportive encouragement of patient  
Provider unequal unfair treatment  
Provider workload  
Providers frustrated by policy  
Racial perceptions of patients  
Relationships with colleagues  
Suggestions for improving services

Appendix 14: Example of data analysis step of categorising codes through table top categories



## Appendix 15. Example of data matrices

### What patient-related factors have a bearing on providers' experience of work? (Facility 2)

Providers	Is personal safety a problem in relation to patients?	What is the effect of patient recognition/appreciation on provider?	What type of patients evoke empathy in providers?	What does provider see as personal risks in the relationship with TB patients	How does provider deal with risk?	What does provider see as Professional risks in the relationship with patients (e.g. challenges for performance; meeting targets)	How does the provider deal with this risk for their prof status (see code on "providers don't give up on difficult clients")
<b>EN (female)</b>	Yes; Is wary of interacting with male patients with a criminal history. Also notes the social context (shebeens, drugs, violence) and challenges for a women in that environment	Proud of herself in that she is doing God's work.	Young teen mothers with TB	Risk of getting infection; worries that she is the only breadwinner in the family; looks after grand-daughter and niece; son had TB; risk of being a women working with high risk; males and following-up defaulters; stress that she constantly thinks of her clients even at home	Infection control (mask, opens windows at home; keeps an eye on g/children); careful/wary in interactions with male clients	Poor compliance, dishonesty in communication; unwillingness to take responsibility for one's health; male patients with a criminal history, drinking	Persevere and not give up on clients (e.g. of female pt from Parklands; chasing her down in Barcelona)
<b>EN (Male)</b>	Yes; context of crime and violence, gangsters hide in clinics	Proud of himself; dream was to become a teacher but feels that he is still 'sort of a teacher' and has helped patients	Patients who miss their visit and stay away from the facility for fear of being scolded/shouted at by the providers; had a personal experience with rude provider	None;	maintains boundaries between personal and prof life	Being required to work outside of scope of practice by community; Defaulting because of alcohol use and rude patients which in his view is provoked by rude provider	not evident from interviews
<b>TB adherence counsellor (female)</b>	Aware of threats to personal safety but is not terribly afraid; can protect herself	Proud, making a difference for a patient and being appreciated feels like a celebrity;	Not evident from interview	Taking patients problems on is detrimental for her health; has a dependents and cannot afford not to work	maintains strict boundaries between personal and professional life; gets debriefing from colleagues	Irritated by 'non-compliant, rude, unwillingness to take responsibility for their health, part among men.	
<b>TB adherence counsellor (Male)</b>	Aware of threats to personal safety but is unafraid		All patients because of the psycho-social impact of the disease; patients who are socio-economically vulnerable and challenged by stigma	None and happy see patients after work who need support; merging of personal/professional boundaries	Does not perceive risk in the reln with patients	"Patients like to complain' even when everything is "100%"; demanding patients	



<b>TB Prof Nurse</b>	<b>No;</b> Aware of threats to personal safety and the reputation of the township but is unafraid	Develop a bond with patients and when they get better feels good	Not evident from interview	Not evident from interview	Not evident from interview	Patients complaining about waiting, their socio-economic status, difficulty in getting the DG; laziness to visit the facility, unwillingness to take responsibility	Not evident from interview
<b>CCWs (female)</b>	<b>Yes;</b> Visiting patients (esp males) in their homes poses a physical threat. Have been threatened with physical violence/rape. Threat also from the male partners of clients	Proud, making a difference for our community; being recognised as someone of importance in the community	Women who have not disclosed to their partners; stigma associated with tabs and changes in body/body image	Being attacked, raped. Living and being part of the community means that prof/personal boundaries are unclear; pts visit them in their homes; risk for children and having to explain to husbands/partners	Avoid difficult clients, report them to the facility, visit difficult clients in pairs	Patients who are unwilling to take responsibility for their health, refuse to disclose and compounded by problems of alcohol abuse. Challenge of physical violence/rape; patients who hide their identity, pretend to be someone else contributing to CCWs making multiple visits, unable to locate pt; compromises CCW reputation (lying); contributes to conflict with mgt	Report to supervisor in the clinic

### Providers reasons to trust management and consequences (Facility 2)

	Reasons to trust	Consequences of trust	Reasons not to trust	Consequences of less trust
<b>Providers</b>				
<b>EN (female)</b>	recognition of efforts	motivated to work harder	changes in policies challenges perceptions of competence	demotivating
<b>EN (Male)</b>	recognition of efforts, opportunities for training	motivated to work harder	unfair mgt practices which do not recognise role as male nurse; lack of position within organisation	demotivated, challenges mgt
<b>TB adherence counsellor (female)</b>	relationship with colleagues, supportive	feels connected to team	nobody who says thank you; working for a cent; No bonus; Province does not care about us; at my NGO there are new cars; money from Lotto but there is nothing they are doing for us; low down in institutional hierarchy.	demotivated
<b>TB adherence counsellor (Male)</b>	relationship with colleagues, supportive; facility has a good reputation	feels connected to team	policies which do not take account of ground realities and indirectly impact provider worker and performance	remains motivated inspite of challenges with workload
<b>TB Prof Nurse</b>	recognition of efforts; targets are perceived as fair and motivating	motivated	not evident	not evident

<b>CCWs (female)</b>	supportive relns with colleagues	connected to team	Challenging reln with supervisor in the facility and co-ordinator, moody, unapproachable; mgt is seen as uncaring, increases workload (e.g. CCW takes over pts of CCW on maternity leave) w/out increase in compensation; left with little choice; supervisors don't always believe (didn't really follow-up on client, sitting at home, believing client over CCW); labelled as lazy and liars; poor salaries compared with workload	demotivating but concerns for community/status over-ride
<b>Doctor</b>	recognition of efforts; good reln with facility manager	motivated	not evident	not evident